DOCUMENT RESUME

ED 333 631 EC 300 384

AUTHOR	Wright, Barbara; King, Martha P.
TITLE	Americans with Developmental Disabilities: Policy Directions for the States.
INSTITUTION	National Conference of State Legislatures, Denver, CO.
REPORT NO	ISBN-1-55516-690-3
PUB DATE	Feb 91
NOTE	61p.
AVAILABLE FROM	National Conference of State Legislatures, 1560 Broadway, Suite 700, Denver, CO 80202 ($10.00 plus postage and handling).
PUB TYPE	Viewpoints (Opinion/Position Papers, Essays, etc.) (120)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Community Programs; *Developmental Disabilities; *Early Intervention; Education Work Relationship; Family Programs; *Financial Support; Mental Retardation; Needs Assessment; *Supported Employment; *Transitional Programs
IDENTIFIERS	National Conference of State Legislatures

ABSTRACT

This Task Force report offers recommendations to state legislatures in the following policy areas: early intervention, family support, transition services, community living, supported employment, and funding for persons with developmental disabilities. Stressed is a consumer orientation which focuses on individual and family strengths and needs. For each policy area the report provides background information including why legislators should be concerned, federal activities, and state activities as well as the specific Task Force recommendations for state actions. Major recommendations in each policy area include: establish a statewide collaborative system of intervention services; create and fund family support programs for families who provide care at home for their disabled children; designate a lead agency to coordinate activities needed for a transition program for young people with developmental disabilities; increase resources for typical community residences and support services tailored to individual needs; develop strong public-private partnerships to encourage the employment of people with developmental disabilities; and develop financial goals for community services and support systems for this population. Appendixes include a statement by the National Conference of State Legislatures; a table giving state fiscal efforts in this area; and a list of 19 organizational resources. Footnotes document the report's findings and a list of acronyms is provided. (DB)

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Americans with Developmental Disabilities

Policy Directions for the States

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Report of the Task Force on Developmental Disabilities
National Conference of State Legislatures

The National Conference of State Legislatures serves the legislators and staffs of the nation's 50 states, its commonwealths, and territories.

NCSL was created in January 1975 from the merger of three organizations that served or represented state legislatures. NCSL is a nonpartisan organization with three objectives:

- To improve the quality and effectiveness of state legislatures;
- To foster interstate communication and cooperation; and
- To ensure states a strong, cohesive voice in the federal system.

AMERICANS WITH DEVELOPMENTAL DISABILITIES

Policy Directions for the States

by

Barbara Wright

Martha P. King

and the

NCSL Task Force on Developmental Disabilities

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February 1991

Pub. 910 3002

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ISBN 1-55516-690-3

Pub. 910 3002

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FOREWORD

The Task Force on Developmental Disabilities of the National Conference of State Legislatures (NCSL) was established in 1990 by NCSL President Lee A. Daniels, house minority leader in Illinois. Representative Daniels charged the task force to recommend state legislation for people with developmental disabilities and their families.

In response, the Task Force on Developmental Disabilities proudly issues this publication, which provides background and makes recommendations for state legislatures in the following policy areas: early intervention, family support, transition services, community living, supported employment, and funding.

The task force based its work on a principle of consumer-focused service, which recognizes that each individual and family has unique strengths and needs that change over time. The task force aims toward the future with a vision of how to improve services for persons with developmental disabilities and their families.

The task force recognizes that existing programs, facilities, and practices represent concerted efforts by states to provide the most appropriate services to citizens with developmental disabilities. Many task force members were introduced for the first time to the forces of change that demand new structural approaches to services for persons with developmental disabilities, changes brought about largely by dedicated and vocal persons with disabilities and their advocates.

This publication represents task force recommendations for state action to change the structure of services to persons with developmental disabilities over a period of time. Task force members hope this report assists legislators and other policymakers to improve their service systems for persons with developmental disabilities who desire to live, learn, work, and play as inclusive members of their communities.

This document concludes the first-year work of the task force. Other projects included: development of a NCSL Memorial, adopted at the NCSL business meeting in August 1990 (page 39 of this document); and co-sponsorship of the February 28 to March 2, 1991, national conference, "Americans with Developmental Disabilities: Policy Directions for the States," in Chicago. In the future, the task force may make recommendations for NCSL involvement in federal policies that affect states' services to persons with developmental disabilities, address health-care service and access issues, address state implementation of the federal Americans with Disabilities Act, and address prevention activities to lower the incidence rate of developmental disabilities.

William T. Pound
Executive Director
NCSL
February 1991

Pub. 910 3002

ACKNOWLEDGMENTS

This publication was produced by the NCSL Task Force on Developmental Disabilities. Printing costs were covered by a subcontract with the Human Services Research Institute (HSRI) under Grant no. 90DD0156 from the Administration on Developmental Disabilities. The views expressed in this document do not necessarily represent the opinions or policy of the Administration on Developmental Disabilities.

NCSL and members of the task force gratefully acknowledge the special contributions of Allan I. Bergman, deputy director of the United Cerebral Palsy Associations (UCPA), Inc., who contributed a great deal of time and expertise and served as a valuable consultant to the task force throughout its first year; Robert M. Gettings, executive director of the National Association of State Mental Retardation Program Directors, Inc., who contributed his expertise and many hours to improve the initial drafts of the publication; and John Agosta, HSRI, who authored the first draft of the family support section.

NCSL and members of the task force are grateful to the following persons who contributed to the policy papers and reviewed drafts of this publication: David Braddock and Richard Hemp, University Affiliated Program (UAP) in Developmental Disabilities, The University of Illinois at Chicago; Valerie Bradley, HSRI; Michael Callahan, UCPA Supported Employment Project in Gautier, Mississippi; Tecla Jaskulski, social policy consultant; Jay Klein, Institute on Disability (UAP), University of New Hampshire; K. Charlie Lakin, Institute on Community Integration (UAP), University of Minnesota; Christina Metzler, National Association of Developmental Disabilities Councils; and Cathy Ficker Terrill, Illinois Planning Council on Developmental Disabilities.

Several NCSL staff also deserve recognition for their contributions: Louise Bauer, graduate-student intern, who spent many hours gathering state information and assisting with research; Candace Romig, group director for Human Services, Sheri Steisel, committee director of the Human Services Committee, and Joy Johnson Wilson, senior committee director of the Health Committee, who reviewed drafts; Sharon Schwoch, book editor, who oversaw production of the publication; Marion McDonald, contract editor for NCSL, who edited the publication; and Joyce Johnson, administrative assistant, who was responsible for word processing, layout, and design.

Numerous others provided information about state programs that are highlighted in the publication. These include state agency administrators, legislative staff, and persons from state developmental disabilities councils. Many are listed as state contacts throughout the document or are credited in the Notes. NCSL staff and task force members appreciate their time and expertise.

Illustrations: Artwork reprinted with permission of the artist, Martha Perske, from *Circle of Friends* and *Hope for the Families*, by Robert Perske (Nashville, Tenn.: Abingdon Press).

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INTRODUCTION

A developmental disability is a severe, disabling condition that arises in infancy or childhood; persists indefinitely; and causes problems in language, learning, mobility, and capacity for self-sufficiency. For example, mental retardation, epilepsy, cerebral palsy, and autism are all developmental disabilities. Nearly four million Americans have developmental disabilities, with diverse levels and types of impairments and capabilities.[1] Of these four million people, approximately one million may require an intensive array of services for most of their lives.[2]

People with developmental disabilities often are or have been associated with life in an institution or other setting segregated from the larger society. But perceptions of Americans with developmental disabilities are changing rapidly. Today, many people previously thought to require institutional care now live with their families or in small, supported community residences; use public transportation to work in competitive employment; participate in community recreation activities; and lead integrated lives in the community.

States traditionally have taken the lead in supporting persons with developmental disabilities. In the past 15 years, states have steadily increased their support for community-based developmental disabilities services. States allocate $7.4 billion of the $11.8 billion contributed annually by state and federal governments to fund programs supported by state agencies for developmental disabilities.[3] In addition, states appropriate close to $4.8 billion per year to schools for special education services for students with mental retardation.[4]

Most of the innovations in approaches that have occurred over the past two decades have been generated at the state and local levels. These innovations include allowing people with disabilities to choose where and how they want to live and in what activities they want to participate, empowering families and consumers to take an active role in decisions affecting their lives, and emphasizing support for people in natural settings, including the following:

- Children growing up in a home with their family, rather than in an institution;
- Children going to a neighborhood day care center or home, instead of to a segregated program for children with disabilities;
- Children attending regular preschool and neighborhood school classes, rather than being isolated in a "special" class;
- Children and adults with disabilities participating in community activities with family and friends instead of being isolated with others who have disabilities; and
- Persons with disabilities working side by side with persons without such disabilities in a competitive job, rather than being segregated in sheltered workshops.

Consumers and advocates are turning to states for continued leadership in meeting the needs and desires of their citizens with disabilities. With the new emphasis on consumer and family empowerment, state policymakers across the country are being asked to seek input from consumers and to redefine policy goals for their citizens with developmental disabilities.

Opportunities for people with developmental disabilities to exercise competence and live lives similar to their peers without disabilities will continue to expand rapidly as a result of the following federal acts:

- *Americans with Disabilities Act of 1990 (ADA) (P.L. 101-336).* This comprehensive civil rights legislation creates sweeping protection of rights in the areas of employment, public accommodation, transportation, and telecommunications for people with disabilities, including developmental disabilities. All newly purchased buses must be equipped with lifts. Private entities, such as movie theaters, day care centers, schools, hotels, restaurants, law offices, golf courses, grocery stores, libraries, beauty parlors, and numerous other businesses and facilities, will be required to make their buildings accessible to people with disabilities. Employers also must make "reasonable accommodation" for persons with disabilities, whether it be through redesigning jobs, modifying facilities, or supplying readers or interpreters. The ADA will open up vast new opportunities for people with disabilities to live, work, play, travel, or shop in the community.

- *Developmental Disabilities Assistance and Bill of Rights Act (P.L. 101-496).* This law aims to enable people with developmental disabilities to achieve their maximum potential through three key concepts, which have become goals for many programs serving this population nationwide: independence, productivity, and integration into the community. The act provides monies to fund a developmental disabilities planning council and a protection and advocacy system in each state, and a network of university-affiliated programs across the country. The work of the developmental disabilities councils is supported by small grants to states, which may be used to fund activities to support improvements in the service system. For example, monies may be used to demonstrate innovations, such as family support, training for parents, research on funding alternatives, and activities to assist policymakers in addressing critical issues. Funds also are provided for protection and advocacy systems, which represent people with developmental disabilities in areas such as special education, guardianship, abuse and neglect, transportation, housing, and employment discrimination. The university-affiliated programs provide training to professional and paraprofessional staff, with emphasis on community and individual services.

- *Fair Housing Amendments Act of 1988 (FHAA) (P.L. 100-430).* The FHAA prohibits discrimination in the sale, rental, or financing of housing to persons with disabilities and also sets standards of accessibility for newly constructed multi-family housing. In addition, the 1988 act addresses discrimination against group homes and other community residences by prohibiting the application of special zoning, land-use requirements, and other restrictive actions that have the effect of limiting the ability of persons with disabilities to live in the community residence of their choice.

State legislators will be making new choices as a result of these important acts. In this time of transition and new opportunities, a number of states are defining principles upon which services to people with developmental disabilities should be based. These principles are based on values that recognize the primacy of the American family and the importance of creating and supporting programs and services that enable people with developmental disabilities to experience presence and participation in community life. Most people, including those with developmental disabilities, want good relationships with family and friends, respect and dignity, opportunities to develop and exercise competence, and opportunities to contribute to community life and make choices about their future.

Policies based on these values result in new residential, educational, and employment alternatives for persons with developmental disabilities. This publication contains background information about early intervention, family support, transition services, community living, and supported employment, and makes recommendations for state legislative actions concerning each area. Changes in the way states structure services that support individuals with developmental

disabilities require changes in funding structures. Therefore, a section on funding also is included in this publication, with recommendations for state actions.

In considering each topic area, legislators and other policymakers need to realize the critical importance of building an "infrastructure" capable of supporting the delivery of direct services, including the maintenance of a system to ensure the quality and accessibility of such services. In the absence of an administrative infrastructure capable of supporting sound systemwide planning, development, and management, individual service initiatives are likely to be carried out in a well-meaning, but haphazard and uncoordinated manner. Effective management of large, complex service systems requires access to timely data on numerous dimensions of systemwide performance, strategic planning, and development capabilities. A clearly articulated approach to ensuring that all participants receive high quality services and support systems also is needed. Policymakers need to be aware that investment in indirect supports is essential to maintaining a smoothly functioning service delivery system.

Among the actions legislators and program administrators can take to help ensure quality in their programs are the following: develop program and services standards; require licensure for service providers and facilities; encourage staff training; provide for case management and service coordination; establish a mechanism to monitor services, service outcomes, and consumer satisfaction; implement both a management information system and an information and referral system; and obtain technical assistance from others who have experience with related programs and services.

EARLY INTERVENTION

When Elizabeth was 10 months old, she could not crawl, sit up, hear, or "babble." Her parents felt extremely fortunate to find an early intervention program near their home. Every week, Elizabeth and her parents went to the program so she could receive speech therapy, physical therapy, and occupational therapy. In occupational therapy, the child was proud to learn how to use her fingers so she could pick up a Cheerio and put it into her mouth. In physical therapy, she learned how to sit up, then to crawl, and to walk when she was two, with the aid of orthotics that kept her from falling so much. Elizabeth's parents also received training so that they could work with her between weekly therapy sessions. In addition, she learned sign language to communicate with others. Now at age four, Elizabeth can run and jump, and she is learning to speak now that medication restored her hearing. Elizabeth's parents report that early intervention services have made a remarkable difference in their lives and in hers. She is looking forward to joining her friends in school.

Introduction

Early intervention services are designed to prevent, remediate, or reduce the negative effects of delays and disabilities in early development. Assistance to the family and the child with delays may include developmental, educational, therapeutic, technological, and social services. Early identification and treatment of a child's developmental delays promote the optimal development of the child and prevent the emergence of more severe and costly problems later on. Early intervention services typically cover the period between birth and age three.

Children with developmental delays are those who, at birth or shortly thereafter, are diagnosed as having a genetic malformation, birth injury, or serious chronic illness that results in delayed or dysfunctional physical or mental development in major skill areas. Developmental delays result from mental retardation, cerebral palsy, muscular dystrophy, cystic fibrosis, congenital heart disorders or serious heart disease, neural tube defects such as spina bifida, and fetal alcohol syndrome and drug addiction. Infants and toddlers who experience sensory impairment, emotional disorders, or neurologically based learning deficiencies also may have delayed development. Experts estimate that between 3 and 8 percent of all children at birth to age three have developmental delays, established conditions such as Down's syndrome or cerebral palsy, or multiple risk factors.[5]

Early intervention services include family training, counseling, and home visits; respite care; speech pathology and audiology; occupational therapy; physical therapy; assistive technology; psychological, nutrition, and case management services; transportation; medical services for diagnostic or evaluation purposes; nursing services; early identification, screening, and assessment services; and health services necessary to enable the infant or toddler to benefit from the other early intervention services. Depending on the child and family, the type, intensity, and duration of services vary considerably. For example, one family may need one or two services a few hours per week, while others may need full-day or full-week programs that provide numerous services. Services are provided by a variety of professionals, including physicians, public health nurses, nutrition specialists, physical and occupational therapists, speech and language therapists, social workers, and psychologists.

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Early intervention services should serve children in natural settings where infants and toddlers typically are found, such as the family's home, day-care centers, playgrounds, religious institutions, and other community settings. The trend is for the services to come to the child, rather than requiring the family to take the child to the services. Services should be flexible in meeting the needs of families with different lifestyles, cultures, schedules, and priorities.

The best early intervention programs recognize the family as the major caregiver for the child and incorporate the parents as active partners in planning for the child's needs. The family has the knowledge and information needed by professionals to determine how best to meet its child's needs. Parents should be able to choose from an array of services those that best meet the needs of the child with the least amount of inconvenience for the family.

Why Legislators Should Be Concerned

Research verifies the value of public investment in improving the lives of our youngest children. Money spent on early intervention services can significantly reduce the cost of special education services later in the child's life, lower the demand for institutional admissions and other costly human service interventions, and result in higher projected lifetime earnings. Higher wages result in higher income taxes and reduced income maintenance payments.

States also should recognize that the best way to reduce the number of children with developmental delays is to ensure the birth of healthy babies. More than $2.5 billion is spent annually on intensive care for newborns, primarily for low birthweight babies. About 11,000 of these babies have long-term disabilities that result from being too small.[6] Legislators should support prenatal care programs as well as early intervention programs.

State legislatures have a critical role to play in implementing the provisions of the federal Program for Infants, Toddlers, and Families (described next under Federal Activities), either through the passage of legislation, or by providing policy direction and oversight. The core assumptions behind the federal law -- that families are active partners and know what is best for their children -- require fundamental changes in the way early intervention services are financed, administered, and provided.

For state legislatures that choose to build upon their existing efforts in early intervention rather than participate in the federal program, it is important to recognize the public policy benefits of an early intervention program that is family- and community-centered.

Federal Activities

Individuals with Disabilities Education Act (IDEA) (P.L. 101-476). In 1990, Congress reauthorized the Education of the Handicapped Act (EHA), which is the landmark federal legislation concerning education for students with disabilities. During its reauthorization, EHA was renamed the "Individuals with Disabilities Education Act." The law contains Parts A through H. Part B is permanently authorized and provides funds to local education agencies to help pay the excess costs of educating students with disabilities. All other parts of IDEA are discretionary and must be reauthorized periodically. Provisions concerning early intervention include the following:

- *Program for Infants, Toddlers, and Families (Part H of IDEA, originally enacted as Title I of P.L. 99-457).* In recognition of the value of early intervention, Congress amended IDEA in 1986 to create the new Part H program for services to infants, toddlers, and families, commonly referred to as "Part H" or P.L. 99-457. This discretionary program provides financial assistance to help states develop and implement a statewide, comprehensive, coordinated, multidisciplinary interagency program of early intervention services for infants and toddlers with developmental disabilities or with conditions that place them at risk of delays.

  To receive funds under Part H, participating states must designate a lead agency to develop interagency agreements, resolve disputes, and administer funding. Congress appropriated $79.5 million in FY 1990 and $117.6 million in FY 1991 to help state agencies coordinate and deliver improved early intervention services. The federal money is not meant to fund direct services, although some of it may be used to create services that did not exist before. The program's five-year phase-in period, now in its fourth year, gives states flexibility in structuring and implementing their own plans.

- *Federal Pre-School Program (Part B of IDEA, originally enacted as Title II of P.L. 99-457).* "Part B" of IDEA is also known as the Education for All Handicapped Children Act of 1975 (P.L. 94-142). As amended, Part B now requires states to ensure that all eligible children with disabilities, beginning at age three, receive a free and appropriate public education by the 1991-92 school year. States must meet this requirement to receive any federal funds for children counted in preschool under federal special education grant-in-aid formulas.

Medicaid. This federally matched, state-run program provides medical care for low-income persons who receive public assistance, including Supplemental Security Income (SSI), and Aid to Families with Dependent Children. Important federal changes to Medicaid that affect early intervention services include new requirements for screening and treating eligible children and new requirements for expanding Medicaid eligibility.

- *Early and Periodic Screening, Diagnosis and Treatment (EPSDT).* EPSDT is a Medicaid service that must be provided by state Medicaid programs and that covers eligible children from birth to age 21. As of April 1, 1990, states are required to provide periodic screening and assessment for eligible children and youth. If needed, states must provide treatment to correct or ameliorate any physical or mental problems identified during the EPSDT screening and assessment process. "Medically necessary" treatment must be provided as a Medicaid-reimbursable service even if the service is not normally covered under the state's Medicaid plan. For example, if an eligible child is determined to need speech therapy and a hearing aid, both of which are optional services under federal Medicaid regulations, a state must provide these services even if they are not in its Medicaid plan.

- *Medicaid expansion initiatives.* States now must extend Medicaid eligibility to children between birth and age six and pregnant women in families with incomes up to 133 percent of the federal poverty level (FPL). States have the option of covering these populations with family incomes up to 185 percent of the FPL. States also may cover children between ages six and 19 with family incomes up to the FPL. Effective July 1, 1991, states must begin phasing in Medicaid coverage for children born after September 30, 1983, who live in families with incomes at or below the federal poverty level. By the year 2002, all such youth under age 19 will be entitled to Medicaid.

Maternal and Child Health block grant. This block grant enables states to develop or enhance systems to ensure that children with special medical needs have access to primary health care

services. Every four federal dollars must be matched by three state dollars. States have the discretion to target some of these funds for primary prevention and prenatal care, as well as for early intervention services.

Crisis nurseries and respite care. An extension of the Temporary Child Care for Handicapped Children and Crisis Nursery Act of 1986 (P.L. 101-127), this program makes federal grants to states to fund agencies and organizations that provide respite care services for children with disabilities and nurseries for children in crisis because of abuse or neglect. Congress appropriated $5 million for this program in FY 1989 and has allocated $11.3 million for FY 1991. The program has the potential to become a more significant source of support for children with disabilities and their families in the future.

Technical assistance and training. With passage of P.L. 99-457, the federal government made an effort to advise states on policy planning and intervention models nationwide. This technical assistance and training is available through the following:

- *National Early Childhood Technical Assistance System (NEC*TAS).* NEC*TAS, which is coordinated through the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill, is funded by the federal Office of Special Education Programs to analyze the implementation of Part H. More information about NEC*TAS is contained in Appendix C.

- *Regional Resource Centers (RRCs).* RRCs in each federal region have added early intervention specialists to help states develop and implement early intervention and preschool policy.

Other federal programs. Funding for early intervention services may also be obtained through the following federal programs: Alcohol, Drug Abuse, and Mental Health block grant; Indian Health Service; Migrant Health Service; Preventative Health and Health Services block grant; Health Care for the Homeless (authorized by the Stewart B. McKinney Homeless Assistance Act); Community Health Centers; Social Services block grant; Services for Deaf-Blind Children and Youth; Head Start; Technology-Related Assistance for Individuals with Disabilities Act; and Assistance for Education of All Handicapped Children.

State Activities

All 50 states, the District of Columbia, Indian Tribes, the Commonwealth of Puerto Rico, and the other commonwealths and territories are receiving some federal funds to plan for implementation of Part H services under the federal Program for Infants, Toddlers, and Families. States such as Washington have hired additional staff with the requirements under the law. Others, like Oregon, have relied on grass-roots participation in developing policy.[7]

Most states are continuing to move toward full implementation of services under Part H. Between 15 and 20 states are wrestling with whether to continue with their plans, once the full-service requirements become effective in the fifth year, or whether to rely on their own programs. Before deciding, states should examine the fiscal consequences of full implementation of a comprehensive early intervention system accessible to all infants and toddlers with developmental disabilities or delays. The decision should be based on the state's goals for what it wants to accomplish through early intervention services.

Before the federal Program for Infants, Toddlers, and Families was passed, Iowa, Maryland, Minnesota, Nebraska, New Jersey, and South Dakota already had created an entitlement to early intervention services for eligible children, from birth. Since enactment of P.L. 99-457, at least three states -- Hawaii, Louisiana, and Pennsylvania -- have passed legislation creating an entitlement for Part H services.[8]

Early intervention programs in Texas, Maine, Colorado, and California reflect the values of coordinated, family-centered, flexible services envisioned by Part H of IDEA, the Program for Infants, Toddlers, and Families.

Texas. Texas was among the first states to pass legislation to develop services for infants and toddlers with developmental delays. The state's 1981 early childhood initiative and the Texas Early Childhood Intervention Program (ECI) served as models for the authors of the federal legislation, P.L. 99-457.

The Texas ECI Program is coordinated by the Interagency Council, comprised of representatives from the Departments of Health, Human Services, Mental Health and Mental Retardation, and Education. In FY 1990, the council will distribute approximately $14.2 million in state funds and $5 million in federal funds to local community service programs through a competitive proposal process.

Children from birth through age three and their families receive services delivered by 75 local programs. Services include assessment; physical, occupational, and speech therapy; activities to develop cognitive, social/emotional, and self-help skills; adaptive equipment; and transportation. Families are served through case management, training, counseling, and parent support groups. State office staff monitor the local programs and provide training to local staff to ensure that quality services are provided. In FY 1989, more than 15,000 Texas children received early intervention services. In 1989, 788 children who graduated from early intervention services did not need further services. If these children had required continuing comprehensive services at age three, the annual cost of services would have been $6,000 per pupil, or $4.7 million, according to the Texas Education Agency.[9]

(Contact: Mary Elder, administrator, Early Childhood Intervention, Texas Department of Health, 1100 West 49th Street, Austin, Texas 78756; (512) 458-7673; statutory citation: Tex. Hum. Res. Code Ann. Chap. 73.)

Maine. Maine, a national leader in coordinating services for children, sponsored early intervention services before P.L. 99-457 was passed. Unlike many states, which separate services for infants and toddlers from those for preschool children, Maine's Child Development Services System serves children from birth through age five. The program coordinates services both at the state and local levels, under the Interdepartmental Coordinating Committee for Pre-school Handicapped Children (ICCPHC). The ICCPHC consists of representatives from the Departments of Mental Health and Mental Retardation, Education, and Human Services; private preschool agencies and organizations; and parents. This committee works with 16 Local Coordinating Committees to make interdepartmental services accessible to families throughout the state. Early intervention services consist of 16 components, including screening; evaluations done in the child's home if possible; individualized family service plans; case management; and early childhood teams comprised of parents, the case manager, and an evaluation professional. These teams oversee implementation of an individualized family service plan for each participating family.[10]

(Contact: Susan Mackey-Andrews, director, 87 Winthrop Street, SHS 146, Augusta, Maine 04333; (207) 289-3272; statutory citation: Me. Rev. Stat. Ann. tit. 20, 7702 et seq.)

Colorado. The Colorado Department of Education's Special Education Services Unit is the state's lead agency for Part H of P.L. 99-457. Rather than use Part H funds to expand services to infants and toddlers, Colorado has used the funds to help change people's perceptions about service delivery. Colorado's twofold approach is to empower families to make decisions for their children and to offer services that meet the needs of the children and families. If the family functions better, the child will function better. The program encourages service providers to offer more services in homes during evenings and weekends so working parents can be involved. In 1990, the General Assembly mandated the provision of preschool special education services for children age three and older, in keeping with the requirements of Title II of P.L. 99-457.[11]

(Contact: Elizabeth Soper, senior consultant, Department of Education, Special Education Services, 201 East Colfax, Denver, Colorado 80203; (303) 866-6710; statutory citation: Colo. Rev. Stat. 22-20-103.)

California. California has long provided services to infants and toddlers with disabilities and those at risk of developmental delays. Participation in planning for Part H of P.L. 99-457 has challenged the state to develop a more comprehensive, interagency approach to providing early intervention services. The Department of Developmental Services, the designated lead agency for planning activities, is receiving assistance from the Departments of Alcohol and Drug Programs, Education, Health Services, Mental Health, and Social Services. At the local level, 26 planning areas have been established around the state to help plan and coordinate activities. California has received $22.2 million for its first three years of participation in Part H. Six special research studies have been conducted to identify the programmatic and fiscal impacts of fully implementing Part H services under the federal program.[12]

(Contact: Julie Ann Jackson, assistant deputy director, Children & Family Services, Department of Developmental Services, 1600 9th Street, Room 310, Sacramento, California 95814; (916) 324-2090; statutory citation: Cal. Educ. Code, sec. 56425 et seq.)

Recommendations for State Action

The NCSL Task Force on Developmental Disabilities recommends that state legislatures do the following in the area of early intervention:

a) Identify the goals that the state wants to achieve through early intervention services.

b) Develop a system that empowers families rather than service providers.

c) Establish a statewide collaborative system of early intervention services that works to eliminate duplication and fragmentation and increases cooperation among the programs and agencies at the federal, state, and community levels. These services should do the following:

* Ensure aggressive outreach and case finding to enable families to have information about and easy access to early intervention services.

* Recognize the family as the child's primary caregiver and enhance a family's capacity to meet the special needs of its child.

* Be family- and community-centered.

- View infants and toddlers with special needs as whole people whose needs must be met by service strategies that cut across traditional discipline, program, and funding categories.
- Be integrated into the general network of community support, rather than segregated and isolated.
- Offer flexible hours and options to accommodate families from different ethnic and economic groups and who have different values and priorities.
- Identify a child's problem early on -- the earlier the intervention, the greater its effects will be.
- Be provided in settings where children normally go, such as day-care centers, preschools, religious institutions, family medical clinics, and play groups.

d) Designate a lead agency for early intervention (or work with the existing lead agency) to ensure that interagency cooperation and collaboration become a reality.

e) Identify both public and private sources of funding, including private health insurance, to pay for early intervention services.

f) Encourage education for service providers about appropriate screening and referral methods and available resources, such as pediatricians, nurses, hospital and clinic social workers, and day-care providers.

g) Include families in policy development at both the state and local levels and involve them from the initial planning stages through the development and implementation of programs.

h) Make special provisions to require accountability for children with special needs who are in public custody, without families to advocate for them.

i) Institute ongoing efforts to monitor the quality and effectiveness of the state's early intervention services.

Pub. 910 3002

FAMILY SUPPORT

When it was time to release Brittany from the hospital, her parents were urged to put her in an institution. Brittany was blind, immobile, and had a feeding tube. Her parents knew she had minimum brain activity, but they wanted to give her every opportunity. A lot of people told them they were fools for not putting her into an institution. "It's crazy the state would pay $4,000 a month to keep her in an institution, but wouldn't even provide us with medical insurance and the support services we need at much less cost," report her parents. "But we had to do what we had to do for our daughter."

Introduction

The birth of a child with a severe disability or chronic illness creates a crisis for the family and all involved. The level of difficulty experienced by the family depends on the degree of the family member's disability, the presence of challenging needs and behaviors, family characteristics, specific parenting patterns, the family's capacity for coping, and, most of all, the availability of community support services. Despite the challenges, most families reject out-of-home alternatives in favor of continued care at home, especially during the child's early years. These families need services and support systems that are comprehensive, flexible, well-coordinated, family-centered, community-based, and integrated within existing community networks. Services should also enhance a family's understanding of, and response to, its child's disability and available resources.

Increasingly, states are moving away from a traditional, provider-driven service system that often separates children from their families, to a system that empowers families to participate in the process and to choose services that best meet their needs, based on their own circumstances and the particular disabilities of their family member. State legislatures that are formulating policy for family support programs should take into account the following key points:

- Assistance with at-home care enhances a family's capacity to provide care and improves the quality of life for the entire family, including the member with a disability.
- Responsive family support programs provide a wide array of support services for families, whether they are biological, foster, or adoptive. Families' needs vary, and each family should be encouraged to select those services that are most appropriate to build upon its strengths and to meet its needs.
- Support services should be available to families from the onset of the disability and should be designed to reach out to families.
- Access to family support services should be timely and convenient for families.
- As the person with a disability reaches adulthood, the focus of support programs should shift to choices for the individual, whether he or she lives with the family or in another community setting.

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- The public sector cannot be counted on to meet all family needs. Support services should build on the framework found in the family, the neighborhood, and the community. Employers and private health insurance carriers also should be called on to provide support.

- Families should be allowed to control resources, making the system less "provider-driven" and more "consumer-driven."

- Children with disabilities benefit most from training in natural settings where they can learn independent living and work skills that will enable them to live in the community once they become adults or choose to live away from the family home.

- Strengthening the family structure may be less costly to the state than funding expensive alternative residential options for children.

Why Legislators Should Be Concerned

Families that have a member with a developmental disability cope with extraordinary circumstances and needs, emotional stress, time demands, and financial costs. State lawmakers need to be aware of ways that state policies can help preserve these families, rather than inadvertently encourage them to break apart. Without the necessary support systems, families may face the difficult choice of placing a member in an institution or other out-of-home setting, usually at great emotional cost to the family and great economic cost to the state. In some cases, families have impoverished themselves to qualify for Medicaid services or have given up guardianship in order to receive services.

In addition to their concern for family preservation, state legislators are very conscious of the costs of providing services. Home care is less expensive than institutional care for persons with developmental disabilities. The 1988 average per diem rate at an institution for people with developmental disabilities was $153.54, or $56,042 per year. Although state Medicaid matching rates vary, the average rate was 45 percent, or $25,219 in state funds, to support one person in an institution during 1988.[13] In contrast, the average annual family subsidy payment in the United States was $2,567 in 1988.[14] Cash assistance to families must be supplemented with family support services, case management, and other programs to provide a reliable alternative to institutionalization. Nevertheless, on an individual basis, the total cost to the state for home care is less than the cost of institutional care.

A study by the Center on Human Policy at Syracuse University evaluated the costs of serving children with severe disabilities who have institutional histories and are currently living with families. The study found that, on average, the cost of care for children in these families was one-fourth to one-fifth that of institutional care.[15] Family support programs help keep families together and offer an effective use of public dollars.

Legislators need to be aware of their own state policies that encourage costly institutional care and what options exist to prevent out-of-home placements. Unfortunately, the current reimbursement criteria for Medicaid services actually encourage institutional or other out-of-home placement for children with disabilities who need support services. Many families who need help with support services or equipment are ineligible for Medicaid because their income level is too high, even though they may not be able to afford to purchase the needed services and equipment on their own. If the child is placed outside the home, the family's income is no longer taken into account and the child becomes eligible to receive Medicaid-reimbursed services. This policy creates severe

hardship for many families who want their children with serious health problems to live at home. Fortunately, some of the federal options described next may be useful to states that want to assist such families.

Federal Activities

A variety of federal programs provide support and services useful to families who undertake home care for a member with disabilities. These include the following:

Supplemental Security Income. SSI is an income maintenance program that provides a base level of income support for persons who are blind, disabled, or elderly. For children under 18 years old who are living at home, parental income and other resources are taken into account, and only children of very low-income families qualify.

Medicaid. As described on page 3, Medicaid is a medical assistance program for low-income people who meet certain criteria. States adopt their own Medicaid plans, which describe the service options that will be covered. States are required to include nine mandated services and have the option of covering any or all of an additional 34 services, such as physical therapy, speech therapy, and private-duty nursing. Federal regulations require that Medicaid services designated in a state's plan be available statewide and to all Medicaid-eligible residents, unless exceptions are made either through federal actions or through a waiver approved by the federal government after application by a state. States may apply for the following Medicaid waivers that allow some flexibility to cover home care services for persons with developmental disabilities:

- *Home- and Community-Based Services (HCBS) waiver.* Also known as the "2176 waiver," the HCBS waiver allows states to cover certain home- and community-based support services to Medicaid-eligible persons who otherwise would be served in an institutional setting at an equal or higher cost. As of 1990, 41 states offered services to over 50,000 persons with developmental disabilities through this option.[16] Although the majority of these persons are adults, Medicaid-eligible children with disabilities also benefit from this option.

- *Model Waiver Option.* This waiver allows a state to cover optional services that are not otherwise in its Medicaid plan for a small targeted group of persons, such as children who are ventilator dependent. The model waiver, sometimes called the 50/200 waiver, allows Medicaid reimbursement for home care services to a defined population of up to 200 persons per waiver who otherwise would need more costly institutional care.

Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). As mentioned previously, for children with developmental disabilities under 18 years old, parental income usually is taken into consideration in determining a child's eligibility for Medicaid benefits, unless the child is removed from the family setting. States may opt to offer Medicaid services to children with severe disabilities who are living at home without considering family income by modifying the state's Medicaid plan in accordance with Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982. Although 17 states have elected this option, many apply it to a very narrow range of potential beneficiaries.[17]

The Individuals with Disabilities Education Act (P.L. 101-476). As described on page 3, IDEA was formerly called the Education of the Handicapped Act. This landmark legislation is intended to guarantee all children with disabilities, no matter how severe, a free and appropriate public education. Part H, the Program for Infants, Toddlers, and Families (also known as P.L. 99-457) is

the first piece of legislation to recognize families as the primary caregivers for children with disabilities. As described under "Early Intervention," this breakthrough in federal disability policy provides funds to states to create statewide programs of early intervention services by October 1, 1991.

The Temporary Respite and Crisis Nurseries Act (P.L. 101-127). This act makes federal grants to states, on a competitive basis, to fund agencies and organizations that provide respite care for children with disabilities and nurseries for children in crisis because of abuse or neglect.

Other federal programs. Other sources for family support include the following: the Maternal and Child Health block grant (Title V of the Social Security Act), as discussed on page 3; and the Developmental Disabilities Assistance and Bill of Rights Act, as noted on page x.

State Activities

Over the past decade, a majority of states have initiated programs to support families providing home care for a child with a disability. The definition of family support services varies widely among states. Services most commonly offered are case management, respite care, parent education, home adaptations, special equipment, and transportation. Other services may include information and referral, parent and family counseling, peer support groups, homemaker services, attendant care, chore services, in-home nursing services, future planning, and cash assistance.

State family support programs usually provide either services to families through a contract with a third-party agency or cash assistance or vouchers to families who then purchase services from agencies of their choice, often with specified restrictions.

At present, approximately 46 states provide at least some services or other resources to families who care at home for a family member with a disability. More than 30 different services have been identified that offer assistance to families. The most common are respite care, adaptive equipment, and family counseling. Other common services include medical, health, and nutrition services; special clothing; recreation; speech, occupational, and physical therapy; home modifications or repairs; flexible payment for disability-related expenses; and case management. Ten states have a cash subsidy program for families and 17 offer families a combination of financial assistance and support services.[18] However, most existing state programs are rather narrow in scope and are vulnerable to shifting political and budget priorities. Most programs offer limited services to few families, place restrictions on the types of services offered, fail to utilize existing community networks, and are slow to empower family members. Programs in Michigan, Wisconsin, New Hampshire, and Illinois are broader in scope. Nebraska's program, which is more limited, is intended to fill in gaps in existing services.

Michigan. This state pays direct cash subsidies of approximately $243 per month to families with children who have a severe disability. The subsidy helps defray care-related costs, such as specialized equipment, respite care, and home renovation. To qualify for the subsidy, a family must earn less than $60,000 annually and have a child with severe disabilities under age 18. After that age, the person with disabilities becomes eligible for federal Supplemental Security Income. The average cost of the subsidy program is less than $8 per child per day, far less than what might be incurred by a child in a state institution or community residence.

Michigan also has a "permanency planning" program to prevent new institutional placements of children with special needs and a goal of returning all children from state institutions to the community. Institutional placements declined 78 percent between 1977 and 1988. In 1989, fewer than 50 children remained in state centers. The family subsidy and permanency planning programs contributed significantly to this decline. Additional factors included a specialized foster training home program, a stronger network of case management, and family support services provided through local community mental health boards.[19]

(Contact: Susan Arneaud, director, Family Support Services and Subsidy, Department of Mental Health, Lewis Cass Building, Lansing, Michigan 48913; (517) 335-4070; statutory citation: Mich. Comp. Laws 330.1155.)

Wisconsin. This state's Family Support Program helps parents locate the public and private resources they need and provides funds to buy those things that the family needs but cannot obtain through other sources. The state has found that direct assistance to families is more cost-effective than out-of-home placement and more beneficial to the child and family. Wisconsin has made extensive use of Section 134 of the federal Tax Equity and Fiscal Responsibility Act, which allows the state to waive consideration of family income in determining Medicaid eligibility of a child with severe disabilities. The state publicizes the availability of this option and conducts extensive outreach to families who may be eligible.[20]

(Contact: Beverly Doherty, program manager, Department of Health and Social Services, Division of Community Services, P.O. Box 7851, Madison, Wisconsin 53707; (608) 266-7469; statutory citation: Wis. Stat. 46.985.)

New Hampshire. The New Hampshire General Court (the legislature) appropriated close to $3 million for FY 1990-91 to establish a support network for families caring at home for children or adult family members with disabilities. The innovative aspect of this network is the extraordinary amount of power parents have been given to determine what services will be delivered, and how. The parents, who know best what services are needed, are responsible for selecting providers and submitting plans to family support councils. These regional councils, comprised of persons having family members with disabilities, make decisions about the allocation of support services among providers.[21]

(Contact: Ceil Conner, state family support coordinator, State Office B Park South, 105 Pleasant Street, Concord, New Hampshire 03301; (603) 271-5057; statutory citation: N.H. Rev. Stat. Ann. 126-G.)

Illinois. Under one of the nation's newest family support laws, Illinois is implementing two programs, one to benefit families that care for their child at home and the other to provide assistance to adults with disabilities, whether or not they live with their immediate family. Both programs are designed to empower individuals with severe disabilities and their families to design and direct their own array of services to suit their unique strengths, needs, and desires.

Under its Family Assistance Program, Illinois will pay direct monthly cash stipends of $386 to eligible families caring at home for a child who has a severe developmental disability or severe emotional disturbance. The subsidy may be used at the family's discretion for the benefit of the child and the family. To qualify for the stipend, a family must have a federal taxable annual income of less than $50,000 and have an eligible child under age 18 living at home.

The Home-Based Support Services Program is designed for adults with severe developmental disabilities or severe mental illness who live in their family home or in their own home. Participants will receive an individually chosen and tailored array of support services up to a maximum monthly value of $1,158. The adults, together with family members or other representatives, choose the type and amount of support services they need and may change

services or service providers as their needs and desires change. Assistance in obtaining existing services or in meeting unique service needs is provided for all adults under the program. The provider bills the Department of Mental Health and Developmental Disabilities. In FY 1990-91, the program will serve 330 adults at a cost of $4.3 million.[22]

(Contact: Connie Sims, P.A. 86-921 coordinator, Department of Mental Health and Developmental Disabilities, 405 Stratton Office Building, Springfield, Illinois 62765; (217) 782-0632; statutory citations: Ill. Rev. Stat. ch. 91 1/2, sec. 100-59 and sec. 1802 et seq.)

Nebraska. The Disabled Persons and Family Support Program was created to "fill in the gaps" by providing support in community settings for persons with disabilities. Administered by the Department of Social Services, the program originally assisted families financially with disability-related expenses and helped adults with disabilities who needed support to remain employed. In 1988, the Nebraska Legislature allocated additional funding so the program could also serve persons with disabilities who are living independently, either alone or with a caregiver who is not a relative. For persons who receive assistance, the program allows up to $300 per month to purchase items or services that otherwise would not be available to them.

Nebraskans are encouraged to call a toll-free phone number for assistance. In many cases, personnel are able to identify other appropriate funding sources to assist callers, which eliminates the need for financial support from the Disabled Persons and Family Support Program. All applications are reviewed by a committee, which includes representatives from the League of Human Dignity, the Easter Seals Society, vocational rehabilitation, special education, developmental disabilities, the Department on Aging, and the Department of Social Services.[23]

(Contact: Senator Don Wesely, chairman, Health and Human Services Committee, State Capitol Building, Room 1402, Lincoln, Nebraska 68509; (402)-2610; statutory citation: Neb. Rev. Stat. 68-1501 et seq.)

Recommendations for State Action

The NCSL Task Force on Developmental Disabilities recommends that state legislatures do the following in the area of family support:

a) Create and fund family support programs for those families who provide care at home for their children with developmental disabilities, adhering to the following guiding principles:

* The program should support the family rather than the service provider.

* All children, regardless of disability, have the right to grow up with a family, biological or otherwise, and need enduring relationships with adults.

* The role families play in providing care at home must be recognized and supported so that family members are enabled and empowered to make informed decisions.

* Means for supporting family efforts should build on existing support networks and natural sources of support within the community and should be culturally sensitive.

b) Provide flexible programs to meet the needs of individual families, recognizing that their needs change over time.

c) Require coordination of all family support-related activities undertaken by state agencies, such as departments of developmental disabilities, education, human resources, public welfare, and mental health.

d) Use all public and private sector resources available to families, including government agencies, private employers, and private health insurers.

e) Ensure adequate training for persons who provide family support.

f) Design all family support initiatives to promote the integration of persons with disabilities into the community.

g) Monitor the quality and effectiveness of all service programs through systematic reviews, which should include input from consumer families.

h) Define family support as a benefit program that is not included as income for purposes of state taxation.

i) Provide independent living and work training to youth with disabilities to facilitate transition into adulthood and to promote independence.

TRANSITION SERVICES

Last year, Teresa graduated from her local high school. She had received special education and related support services since elementary school. At age 13, Teresa started participating in school-sponsored training activities in the community with her teacher and a small group of other students. She learned to shop at a grocery store, take a bus, and order from fast-food restaurants. When she reached age 14, Teresa spent at least two hours during each school day in community-based job training. In school, she had trained in occupations such as food services, domestic home cleaning, and clerical and custodial assistance. When she was ready to leave school, Teresa knew she wanted to be a clerical worker. She already knew how to run a copy machine and felt confident she could do the job. The transition program was able to match her with an employer, and she moved directly from school to an office job. Now Teresa works 20 hours a week and takes the bus to work, a 30-minute ride. "I'm so glad she was able to get a job so she won't forget all the things she learned in school," says her mother. "It's amazing, really, what she can do. I'm proud of her, but, more importantly, she's proud of herself."

Introduction

Each year approximately 35,000 to 40,000 students with developmental disabilities leave special education programs to take their places as adults in the community. To help young people make the transition from school to adult community life, some states implemented transition planning even before the new federal requirements were enacted. Such planning links graduates who have disabilities with community services and is intended to ensure that all students graduate with the skills necessary to enter the work force or to continue their education.

Transition planning is a partnership involving students with disabilities, their families, school and post-school service personnel, local community representatives, employers, and neighbors. The goals are to assist the student in choosing a living situation, to ensure that the student graduates with community living skills and a variety of job skills, and to assist the student in choosing a job, so he or she can become a tax-paying, productive citizen in the community. Because young people with disabilities have different levels of impairments and capabilities, transition planning needs to be flexible enough to meet a variety of needs. Such planning also should begin early, with the expectation that all children will leave school with functional skills for adulthood.

To be effective, transition planning should be an inherent component of the student's curriculum. Progressive schools are providing a curriculum that prepares the students for the changes and demands of life after high school. Some schools are offering up to five paid community work experiences as part of their program prior to graduation. Innovative programs offer skills training in natural rather than simulated environments, including the home and work places such as grocery stores, offices, and restaurants.

The transition years are difficult for everyone, including young adults with developmental disabilities. They leave the structured environment of school and go out into the community, facing its bewildering maze of public and private agencies, which often have long waiting lists for services. At this point, specific mechanisms need to be in place to link the exiting students with

community services and support; otherwise, the students risk falling through the cracks or being placed in a segregated program or facility.

The best transition planning involves consumers and parents as active partners in mapping the educational experience and the years after graduation. Some states have developed programs that train parents as case coordinators for their children to help guide them through the maze of available services. Others empower parents through representation on policymaking bodies and involve the parents in individualized planning for their children. The most innovative states envision the entire school experience as transitional, viewing the purpose of education as preparing students to participate and contribute in the community.

While states have made advances in addressing the needs of students leaving the education system, significant barriers remain. Often there is insufficient coordination between schools and community services agencies. In addition, shortages exist in community programs. Young people exiting high school often are in direct competition for community services with people who are leaving institutions and others who already are on waiting lists for community services. Furthermore, many students do not graduate with the skills necessary to join the work force or to continue their education. Even when graduates choose one of these options, states usually do not readily provide support in these environments. To ensure students a smooth transition to community life, some states are requiring transitional planning early in the educational experience for all students with disabilities. Other states are providing mechanisms at the state and local levels to help students move from school to the community without an interruption of services.

Why Legislators Should Be Concerned

Since enactment of the federal Education of the Handicapped Act, now called IDEA, a whole generation of children has benefited from special education. Parents have seen the potential for their youngsters to grow and change and lead productive lives. Today's graduating students with disabilities have spent their entire school careers receiving special education services; they now need community support services to become working and participating members of adult society.

Many parents feel that the money invested in the children during their school years is wasted when these individuals are forced into idleness due to lack of programs or lack of linkages to existing programs. States can protect their significant investment and enhance the lives of their citizens with disabilities by supporting transition services. These services will open up opportunities for young adults with disabilities to use the confidence and skills learned in school and to become productive, contributing members of society.

Federal Activities

The Individuals with Disabilities Education Act requires schools to prepare an Individualized Education Program (IEP), with the help of parents and teachers, to guide each student's education. Amendments to the act in 1990 require that transitional planning be incorporated into the IEP.

Federal assistance for employment, education, training, and support is available through the Rehabilitation Act of 1973 and the Job Training Partnership Act. An explanation of these federal sources can be found under "Supported Employment," on page 29.

Federal programs that assist people with developmental disabilities to obtain housing and community supports include the following: Medicaid's Home- and Community-Based Services waiver, Medicaid's Model Waiver Option, Medicaid's Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) program, the Developmental Disabilities Assistance and Bill of Rights Act, Department of Housing and Urban Development (HUD) Section 8 rent subsidies, and the Fair Housing Amendments Act of 1988. An explanation of these federal sources can be found under "Community Living," on page 23.

State Activities

Even before enactment of recent federal requirements concerning transition planning, several states initiated such planning for their students with disabilities. Among these are Minnesota, New Jersey, Maine, Kansas, California, and Massachusetts.

Minnesota. The State Transition Interagency Committee (STIC) sets policy and facilitates coordination among local and state agencies so that each citizen who has a disability in Minnesota and exits from school will have an opportunity to live and work within the community. The committee is comprised of representatives from the Departments of Education, Human Services, and Jobs and Training; the community colleges; and parent/advocacy groups. An interagency agreement outlines each agency's role and responsibility for transition and includes a summary of services available from each agency to support the transition effort. School districts are required to establish committees at the local level. A state-funded Interagency Office on Transition Services in the Department of Education, mandated by 1986 legislation, is responsible for staffing the STIC and for providing technical assistance to local community interagency teams. Emphasis is placed on linking resources together in a systematic way.

As required by state legislation, the Individualized Education Program must address the student's transition needs by grade nine, or age 14. Parents, students, educators, and adult service providers develop the transition plan together. Decisions include where the individual will live and work, how he or she will travel within the community, what activities will be undertaken for fun and leisure, what medical and legal services the individual will need, and how relationships will be fostered with family and friends. Efforts are made to involve agencies with the student before he or she leaves school so transition to adult life will not result in gaps in service.[24] The Department of Education, in cooperation with the University of Minnesota, has designed a post-school follow-up system for local school districts to collect information about and report on the post-school outcomes of former special education students.[25]

(Contact: Stephanie Corbey, 550 Cedar Street, 8th Floor, Capitol Building, St. Paul, Minnesota 55101; (612) 296-0280; statutory citation: Minn. Stat. 120.17, subdivision 16.)

New Jersey. New Jersey launched a statewide initiative to help 500 public school graduates with developmental disabilities find competitive jobs in the private sector. Job coaches provide direct on-the-job training, working side by side with the employee with disabilities to help him or her learn the necessary skills. The amount of training is tailored to individual needs.

As the employee becomes proficient, the training decreases. When skills are mastered, follow-up services are provided. The job coach periodically returns to the work site to make sure the worker

with disabilities continues to meet the employer's expectations. If problems develop, the job coach provides one-on-one training until the problem is solved. Follow-up services continue as long as the employee with a disability has the job.

The supported employment initiative requires coordination among the Divisions of Vocational Rehabilitation Services, Developmental Disabilities, and Special Education. An interagency agreement outlines each agency's responsibilities. The Division of Special Education uses local education agency case managers to identify students in special education programs who have graduated recently or are about to graduate. The case managers work with the families, since family support has been identified as a critical factor for success.

Support services for the employee remain the responsibility of the Division of Vocational Rehabilitation Services until the training phase is completed and the employee has achieved job stability. At that point, responsibility is transferred to the Division of Developmental Disabilities, which provides long-term support. If a particular job does not work out for an individual, representatives from the three state agencies meet to determine the reasons and what can be done to correct the situation in the future.[26]

(Contact: Tom Major, Division of Developmental Disabilities, CN 726, Trenton, New Jersey 08625; (609) 984-5357.)

Maine. Maine uses an innovative voucher system to fund transition services under a new pilot program. Eligible consumers are persons with mental retardation between the ages of 20 and 26 who are exiting the public school system and living at home or in an unsubsidized foster home. The individual designs his or her own transition program with the help of an interdisciplinary team comprised of the student, family members or guardians, and professionals. The program will pay only for services that are unavailable from other sources, such as Vocational Rehabilitation, Medicaid, or the Job Training and Partnership Act. Services include evaluation, job placement, counseling and follow-up, job coaching, supported employment, transportation, respite care, recreational and leisure activities, and post-secondary education. The services, which are paid for by the Bureau of Mental Retardation, are capped at $12,000 per consumer annually. For FY 1990-91, the appropriation is $344,501.[27]

(Contact: Roger Deschaies, director of the Bureau of Mental Retardation, State House Station 40, Augusta, Maine 04333; (207) 289-4242; statutory citation: Me. Rev. Stat. Ann. tit. 20, sec. 7702 et seq.)

Kansas. Transition planning services are available for Kansas students with severe disabilities who are at least age 16 or are expected to leave school within two years. The law that created the transition planning program in 1986, directs the Department of Social and Rehabilitation Services to serve as the single point of entry into adult services programs for students in special education programs. Kansas Rehabilitation Services, a division of the department, is the designated lead agency for transition planning. A State Transition Committee, comprised of educators and representatives of parent organizations, community agencies, and state agencies, guided implementation and program development for the state. Local transition councils promote implementation of transition planning and sustain local efforts to develop additional services and to coordinate access to existing services. After obtaining student and parental consent, local education agencies make referrals to one of eight transition counselors at the state level. The student, parents, teachers, and local community program staff develop a transition plan in conjunction with the student's Individual Education Plan.[28]

(Contact: Marnie Brown, Kansas Rehabilitation Services, Biddle Building, 300 SW Oakley, Topeka, Kansas 66606; (913) 296-3911; statutory citation: Kan. Stat. Ann. sec. 75-5372 et seq.)

California. The state Departments of Rehabilitation and Education jointly sponsor the WorkAbility and Transition Partnership Programs to provide comprehensive pre-employment, employment, and work-site training and follow-up for different populations with disabilities. The WorkAbility Program has three components, with the Workability I program serving secondary students who have special needs. Since 1982, WorkAbility I has served over 65,000 secondary students in 297 school districts, providing assessment, career guidance, work experience and training, job search skills, and mobility training. The program is funded by the Department of Education through a combination of state and federal funds, amounting to $5.9 million in 1989-90. The WorkAbility II, WorkAbility III, and Transition Partnership Programs serve different client populations of the Department of Rehabilitation, including students in community colleges or adult schools and persons enrolled in regional occupational centers. These programs are supported with federal rehabilitation funds, state appropriations, and local education dollars. The WorkAbility Program has been recognized by the federal Office of Special Education and Rehabilitative Services as one of the top 10 nationally acclaimed transition programs for youth with disabilities.

(Contact: Keith Foster, administrator, Transition Programs and Services, Department of Rehabilitation, 830 K Street Mall, Sacramento, California 95814; (916) 323-0336.)

Massachusetts. A 1983 state law, commonly referred to as the "Chapter 688 Turning 22 Program," is a transition program for young adults with severe disabilities who either graduate from a special education program, or who no longer are eligible for publicly funded special education because they have reached age 22. The local school systems refer students to the appropriate human services agencies, such as those dealing with mental health, mental retardation, social services, public health, deafness, or blindness. Students with multiple or unusual disabilities are referred directly to the state Bureau of Transitional Planning. The designated state "transitional lead agency" assembles a team to develop an Individual Transition Plan, which maps out the steps required to help the consumer obtain needed services, such as income supports, day programs, employment preparation, residential assistance, and recreational services. The team is comprised of the young adult with a disability, the parent or guardian, representatives from the human services agencies and the school, and an appropriate job training agency. The plan, which must be completed at least six months prior to graduation or the consumer's 22nd birthday, details what services will be provided by which agency, and for how long. The designated lead agency acts as case coordinator for the consumer in the transitional program, which receives about 1,000 referrals annually. Implementation of the program is subject to appropriations by the state legislature. In 1989-90, approximately 200 consumers were served with state funds. Others in need of assistance add their names to waiting lists for various services.[29]

(Contact: Mary Ann Walsh, director, Bureau of Transitional Planning, Executive Office of Human Services, Room 1109, 1 Ashburton Place, Boston, Massachusetts 02108; (617) 727-8050; statutory citation: Mass. Gen. Law Ann. ch. 71, sec. B.)

Recommendations for State Action

The NCSL Task Force on Developmental Disabilities recommends that state legislatures do the following in the area of transition services:

a) Enact legislation designating a lead agency to coordinate the activities of the many different agencies and programs needed to put together a working transition program for young people with developmental disabilities.

b) Develop community services, such as supported housing and jobs, to allow the young adults to make an immediate transition from school to integrated work without wasting years on a waiting list.

c) Encourage the involvement of the young adult and the parents as active partners in planning a transition program.

d) Ensure that transitional planning is a part of the Individualized Education Program by age 14, as required by federal law.

e) Develop quality control measures to ensure that schools provide curricula to prepare students with disabilities for life after school, including a supported or nonsupported job in the community.

f) Encourage the expansion of community-based opportunities for high school students to participate in paid, integrated jobs as part of their education.

g) Seek information from advocacy groups, state government leaders, parents, and educational leaders to learn more about transition needs and existing programs.

h) Utilize community-based jobs rather than center-based "workshop" jobs for students and graduates with disabilities.

i) Ensure continuity of supported employment services from school to community life.

j) Establish a data system to determine whether the desired results are achieved through transition programs.

COMMUNITY LIVING

Bev and Art have been married for four and one-half years. Both work full time, and in their spare time they enjoy going for walks, visiting friends, going to the movies, or going out for dinner. Occasionally they attend city council meetings and offer their opinions on issues. Bev and Art both have mental retardation. Art also has epilepsy, for which he takes daily medication. They met and fell in love in a group home. Now they live in a comfortable, one-bedroom apartment. Art doesn't read, so the push-button telephone and his daily epilepsy medication are color-coded. Initially, the newlyweds received daily assistance from a service provider in a semi-independent living program, but now it's only every other day, or about eight hours a week. Art reports that he likes to wake up to a clock radio instead of a staff person yelling at him. In a group home, he could not leave unless a staff person accompanied him; now he goes out whenever he wishes. Both agree that they prefer living with each other, rather than with 13 strangers.

Introduction

In many states, people with disabilities are living in their own homes in the community with one or two friends of their choice through the assistance of support services targeted to their specific needs. As this happens, the individuals enjoy increased independence and sense of competence; improved relationships with family members and friends; and increased respect, dignity, and feeling of being a part of community life.

Between 1977 and 1989, the number of people with developmental disabilities residing in large institutions dropped 42 percent, to 88,112, the lowest number since 1934.[30] New Hampshire, the first state to close all of its institutions for persons with developmental disabilities, has developed a community-based service system using Medicaid waiver funds. New policies in several other states have been particularly effective in preventing institutional placement of children. Today, many adults around the country who previously were thought to require care in institutions or congregate group homes now live in typical housing and need less than full-time supervision. They participate in community life, with the assistance of individual supports that respond to their particular needs.

By definition, people with developmental disabilities need some form of support because of a physical and/or mental disability. To live in the community, adults may need help with home management, personal care, money management, physical or language skills, socialization skills, and transportation. Making adaptations to the environment, such as building a wheelchair ramp, and providing assistive technology, such as an electronic communication device or a hand brace to assist with movement, frequently allow people with disabilities to live independently. States are developing supported living arrangements for individuals and households of two to three people who, in years past, were considered to need living arrangements in larger institutions or group homes. The aim of such programs is to promote maximum independence and community integration of the individual and maximum efficiency of public resources by providing services that are tailored to each individual's needs.

Instead of being a scattered, experimental initiative, supported living is rapidly replacing development of community residence facilities in a number of states. Nationwide, over 17,000 persons with developmental disabilities lived in semi-independent or supported living

arrangements in 1988. Colorado now serves roughly 700 individuals statewide. North Dakota serves over 500 people; Washington state, 1,000; Minnesota, 1,500; and Illinois, 900. Supported living is flourishing in Florida, Michigan, and Ohio. In addition, supported living exists or is being implemented in Arkansas, Connecticut, Georgia, Missouri, Nevada, New Mexico, Oklahoma, Virginia, and Wisconsin.[31]

Community living is more than a roof over one's head. It is also a feeling of belonging. Today, many service systems are providing opportunities for people with disabilities to develop friendships and ongoing relationships with other people. These opportunities include encouraging consumer choice in roommates, ensuring consumer participation in the employment of support staff, and encouraging relationships between people with disabilities and their peers without disabilities.

Many service systems and agencies are starting to regard parents and consumers as partners in developing and operating services. Innovative community living services across the country have demonstrated that when parents and consumers are empowered to influence policy and programs, cost-effective quality services result.

Why Legislators Should Be Concerned

State legislators should be concerned about expanding community options for people with developmental disabilities because individuals and families increasingly are demanding the choice of community-based integrated living. In addition, legislators want to put dollars where they will reap the maximum return. In an era of tightening budget restrictions, states should not continue to spend a large portion of their budgets on institutional care or large congregate care when virtually all major studies show that people are better off in typical community residences, given the proper supports.

Parents have significant concerns about what will happen to their children when the parents can no longer provide care. The baby boom generation includes over one-half million adults with developmental disabilities, ages 25 to 44, whose parents will soon reach retirement age.[32] In Illinois, estimates range from 3,300 to 14,000 people with developmental disabilities who are 30 years old and older, live with their families, and will require residential alternatives in the next 15 years.[33] States must develop programs to accommodate existing and future generations of people in need of their own homes.

Despite impressive strides in integrated community living, residential options are limited in most states. States are hindered by budgetary limitations and gaps in housing and support services. Affordable rental units that are accessible to people with disabilities are in short supply. In addition, local zoning restrictions often have impeded the development of community-based resources and supports, although a recent federal law prohibits such restrictions, as referenced next under "Federal Activities." Transportation, one of the most needed supports, is still not readily available in most areas. Long waiting lists exist for many community residential programs. Federal assistance is available, but complicated technical regulations often prevent states from taking full advantage of it. Overcoming these obstacles requires leadership, commitment, and creativity on the part of state lawmakers.

Federal Activities

As described under "Funding," beginning on page 32, the largest federally financed program for persons with developmental disabilities is the Intermediate Care Facilities for the Mentally Retarded program, an optional service under Medicaid. The ICFs/MR program pays for 24-hour care in a licensed intermediate care facility for persons with mental retardation and related conditions, such as cerebral palsy, autism, and epilepsy. Because Medicaid coverage of nonmedical home- and community-based services is still highly restricted, federal reimbursement policies encourage states to treat their citizens with developmental disabilities in institutions. Nonetheless, a number of federal programs assist people with developmental disabilities with housing and community services, including the following:

Medicaid Home- and Community-Based Services Program (the "2176 waiver"). As described in the "Family Support" section on page 10, states may apply for a 2176 waiver to use Medicaid funds for a variety of nonmedical home- and community-based support services that are not otherwise included in a state's Medicaid plan.

Medicaid's Model Waiver Option. The Model Waiver Option, also known as the Model 50/200 waiver, is described on page 10.

Community Supported Living Arrangements (CSLA). The Omnibus Budget Reconciliation Act of 1990 establishes an option under Medicaid that will allow a limited number of states to provide community-supported living arrangement services to Medicaid-eligible persons with developmental disabilities. Benefits are exclusively for persons who live in their own home, apartment, family home, or rental unit furnished in a CSLA setting, in which no more than three persons receiving such services reside. Covered services include personal assistance, training and habilitation services, 24-hour emergency assistance, assistive technology, adaptive equipment, and other support services necessary to aid an individual to participate in community activities. Federal matching payments will be capped at $100 million over a five-year period and will be provided to up to eight states selected on a competitive basis.

In addition to providing Medicaid assistance, the federal government also has addressed community services for persons with developmental disabilities through the following laws:

Developmental Disabilities Assistance and Bill of Rights Act (P.L. 101-496). As described in the Introduction on page x, this important federal legislation assists states in planning and promoting community-based services for persons with developmental disabilities.

Department of Housing and Urban Development (HUD) Section 8 rent subsidies. People who earn up to 80 percent of the median income in their area are eligible for Section 8 rent subsidies. In many supported living programs, rent subsidies have proved to be a vital part of helping people with disabilities find affordable housing.

The Fair Housing Amendments Act of 1988 (P.L. 100-430). This act prohibits discriminatory housing practices, such as local zoning restrictions that have prevented the development of residential options for persons with developmental disabilities. The act is described on page x.

Technology-Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407). This act, which is described further on page 29, is intended to expand the availability of assistive technology services for persons with disabilities, enabling them to live more independently.

State Activities

While developing community residential options for its citizens with developmental disabilities over the past decade, New Hampshire phased out its institutional placements. Community living programs in Colorado, Michigan, and Wisconsin are notable for the range of small-scale, family-like residential choices available to people with developmental disabilities. Although local examples are used, each has a statewide program. New programs in Illinois and Ohio also promote independent living.

New Hampshire. New Hampshire no longer operates state institutions for people with developmental disabilities. Instead, the state contracts with 12 Area Agencies for Developmental Services, which are private, nonprofit corporations governed by citizen boards. Area agencies either provide direct services or contract for services, depending on local needs and resources. The local agencies must be redesignated every four years, which involves public participation and comment. New Hampshire's accomplishments include: a complete shift away from institutional settings, using Medicaid waiver funds to provide community options; implementation of a comprehensive system of community early intervention programs; development of an array of community homes (with an average of three residents) for persons who previously were in institutions or lived with their families; and development of hundreds of supported employment placements. Program staff report a high degree of cost efficiency and effectiveness.

(Contact: Richard Lepore, assistant division director for community developmental services, Division of Mental Health and Developmental Services, State Office Park South, 105 Pleasant Street, Concord, New Hampshire 03301; (603) 271-5013.)

Colorado. Centennial Developmental Services, Inc. (CDSI) provides services to adults and children with developmental disabilities in Weld County, using Medicaid HCBS waiver funds. Services are provided to individuals, including those with severe and multiple disabilities, and are tailored to individual needs. CDSI has eliminated the use of group homes and helped people move into smaller, dispersed settings. CDSI uses a variety of settings for people in the residential program. While the majority of consumers live in their own apartments, a small number are served in host homes, which provide a family-like setting. Paid roommates are recruited in some cases to provide companionship and on-going support in the homes. The program is structured so that people with disabilities can learn to make their own choices and take control of many areas of their lives. Other staff services include assistance with domestic and community living skills, help with relationships, and advocacy. Formal programs become part of normal, daily living routines.[34]

(Contact: Richard Pantaleo, co-director of residential services, Centennial Developmental Services, Inc., 3819 St. Vrain, Evans, Colorado 80620; (303) 339-5360.)

Michigan. The Macomb-Oakland Regional Center, located outside of Detroit, has developed more community living arrangements for people with severe disabilities than any other local service system in the country. More than 60 percent of the 1,300 consumers have severe or profound mental retardation. The program has made a strong commitment to keep children who have disabilities with their biological families. For children who do not live with their biological or adopted parents, five residential options are available: foster homes, adult foster care in a setting with up to four people, group homes limited to no more than six people, alternative intermediate service homes for up to six people, and a supported independence program.[35]

(Contact: Nancy Rosenau, director of community services, Macomb-Oakland Regional Center, 16200 19 Mile Road, Mount Clemens, Michigan 48044; (313) 263-8700.)

Wisconsin. Options in Community Living, a private, nonprofit agency in Dane County, provides support services to consumers with disabilities who rent their own houses or apartments. In 1987, the agency worked with approximately 100 people living in the community. Consumers hire their own staff, referred to as attendants. The agency acts as a broker, recruiting attendants and training and teaching consumers how to supervise their own attendants. In some cases, the program uses foster care funding and licensing to arrange for paid roommates who provide companionship and support in the consumers' homes. With special funding from Wisconsin's Community Integration Program (using a Medicaid waiver), Options in Community Living has begun to serve people with challenging needs who previously lived in institutions.[36]

(Contact: Robin Cooper, program manager, Department of Health and Social Services, Division of Community Services, P.O. Box 7851, Madison, Wisconsin 53707; (608) 267-9741; statutory citation: Wis. Stat. 46.278.)

Illinois. The Community Integrated Living Arrangements (CILA) program promotes independence in daily living, economic self-sufficiency, and community integration for people with developmental disabilities or mental illness. The program provides individualized support services, including daytime services, in typical community residences for eight or fewer people with mental disabilities. By the end of FY 90, more than 1,700 people were being served in the CILA program at an annual cost of $40.7 million. By the end of FY 91, the Department of Mental Health and Developmental Disabilities plans to create CILA living units for 700 additional people at an annual cost of $16.1 million.[37]

(Contact: Deborah Murphy, assistant deputy director for community development, Department of Mental Health and Developmental Disabilities, 401 Stratton Office Building, Springfield, Illinois 62765; (217) 782-0638; statutory citation: Ill. Rev. Stat. ch. 91 1/2, sec. 1701.)

Ohio. This state's recently created Supported Living Program furnishes support services to people with developmental disabilities living in non-congregate settings. Program participants select where they want to live, such as an apartment. Participants are expected to meet basic living expenses using their federal Supplemental Security Income payments, other forms of public assistance, and employment earnings. Provider agencies are paid to furnish support services that are identified for each consumer in a personal individual plan. Payments to providers may not exceed $30 per day for each consumer. Participants also are provided with up to $1,800 to assist in setting up their own living arrangement. Efforts are now underway to expand the program to include individuals with more complex disabilities, using Medicaid waiver funds. One initiative focuses on inappropriately placed nursing facility residents and the other on individuals scheduled to move out of an ICF/MR or who are at risk of placement in such a facility.[38]

(Contact: Ann Hinkle, consultant, Department of Mental Retardation and Developmental Disabilities, Division of Community Services, 30 East Broad Street, Room 1220, Columbus, Ohio 43266; (614) 466-7508; statutory citation: Ohio Rev. Code Ann. sec. 5123.182.)

Recommendations for State Action

The NCSL Task Force on Developmental Disabilities recommends that state legislatures do the following in the area of community living:

a) Increase resources for typical community residences and support services tailored to individual needs as the state reduces reliance on Medicaid ICF/MR-reimbursed institutions and other large-group facilities.

b) Provide support systems for adults who choose to live with their families.

c) Separate the housing and support components of service delivery for persons with developmental disabilities. Move away from facility-based service and toward individualized service, regardless of where the individual is living. Encourage programs that emphasize consumer choice in housing and roommates.

d) Promote interdepartmental coordination of support services, such as transportation, medical, and employment services.

e) Expand the availability and scope of individualized programs through Medicaid's Model Waiver Option and the Home- and Community-Based Services waiver, including personal assistance, case management, assistive technology, and therapies.

f) In states that continue to develop licensed group facilities, adopt a policy of limiting new group homes to four to six people, preferably fewer.

g) Encourage dispersed placement of small residences in communities to facilitate maximum integration into community life.

h) Involve consumers and parents in the design, operation, and monitoring of services through participation in oversight boards and commissions.

i) Promote education for real estate developers, landlords, and community housing boards about ways that they can help meet the housing needs of people with developmental disabilities.

j) Develop accessible, affordable housing to meet the needs of people with disabilities and encourage consumer ownership through housing loan programs, cooperative ventures, public/private partnerships, set-aside units designated by developers for people with disabilities, bond issues, vouchers, and other ways to make community living possible.

k) Enact legislation to ensure that community services are designed with the flexibility to be responsive to changing patterns of consumer needs.

SUPPORTED EMPLOYMENT

Mike is a 34-year-old data entry clerk with a county personnel board in Alabama. An employment specialist helped Mike assess his personal interests and vocational skills and find his current position. Because he is severely disabled as a result of cerebral palsy, Mike benefits from several assistive technology devices to perform the demands of the job and to live independently. At work, Mike uses AbleOffice, a modular work station system designed by the Center for Rehabilitation Technology at Georgia Tech. He uses a Minspeak™ Light Talker, which is an augmentative communication device that generates printed speech through a computer. Using a head pointer, Mike can type, operate a computer, dial a telephone, turn pages, and operate his television, VCR, microwave oven, and other appliances at home. For mobility, he either pushes a manual wheelchair with one foot or uses a power wheelchair, which he operates with his chin and mouth.

Mike's lifestyle today is a dramatic change from his 15 years in a nursing home, which he entered at age 15 because he felt that he overburdened his mother. He needed assistance with mobility, feeding, dressing, bathing, toileting, and other daily activities. The nursing home was the only place deemed appropriate within the existing service system for Mike during those years. Fortunately, he was able to relocate to a transitional living center in 1986, where he took classes in money management, food and nutrition, cooking, communication skills, human sexuality, time management, shopping, personal care attendant hiring, and basic computer skills. Since his employment, Mike has moved to his own apartment and uses part of his wages, supplemented with state and federal benefits, to pay for a personal care attendant.

Introduction

With the proper support systems, people with severe disabilities are working in competitive jobs today. Due to advances in assistive technology and on-going support services, the major barriers to employing people with developmental disabilities are coming down. It is perceptions and attitudes that need to change. People who want to work should have an opportunity to contribute to the work force. Having a job increases a person's independence and ability to support himself or herself and decreases reliance on public funds. According to a 1990 survey by the National Association of Developmental Disabilities Councils, fully 90 percent of adults with disabilities report that they are able and want to work.[39]

Assumptions about what constitutes good vocational programming are changing. Individuals with severe disabilities previously were thought to require training at segregated sheltered workshops or adult training centers before entering the work force. Historically, most people entering these training facilities never left. Recent research results raise questions about the benefit of such separate prevocational training. In addition, parents, professionals, and employers have learned, in very practical ways, that the old notions of readiness for employment, which involved helping an individual acquire essential skills before he or she could be placed in a real job, simply do not work very well. Today, professionals are moving toward newer models, such as supported employment, where job coaches help individuals who work in paid jobs, often side by side with workers without disabilities. Essential support services to help people with developmental disabilities participate successfully in work programs include job development and redesign, skills assessment, job

counseling, on-going job coaching, transportation, assistive technology, personal care assistance, money management training, and help with socialization skills.

By working together, legislators, state agency personnel, and business leaders can create a climate in which people with developmental disabilities will have an opportunity to work and receive fair wages and benefits. In almost every state, business leaders who have a track record of employing people with disabilities are taking the lead in redesigning jobs to meet the needs of the employers and the needs of the people with disabilities. Leadership is also required from state agencies and legislators to encourage other members of the business community to hire workers with disabilities who, in turn, can contribute to the economic health of the community. States can set an example by hiring people with disabilities for public sector jobs. Finally, states must make a strong commitment to consumer and family empowerment if supported employment programs are to succeed.

Why Legislators Should Be Concerned

Supported employment is a cost-effective alternative to other vocational programs such as sheltered workshops that are supported by many state governments across the country. The benefits of supported employment are greater because gainfully employed people pay taxes, depend less on public programs, and contribute money to the state economy. Moreover, people who in the past were segregated can enjoy the same community benefits as do people without disabilities.

Despite the advantages of supported employment, the bulk of state employment funds for persons with disabilities still goes to sheltered workshops and other segregated settings. In 1988, federal and state governments spent between $385 and $582 million to place 109,899 people with developmental disabilities in sheltered workshops at a per capita rate between $3,500 and $5,300. In the same year, only $62 million was spent on 16,458 people in supported employment, at a per capita rate of $3,767.[40] The challenge facing state legislators is to develop methods to transfer people currently in day programs and sheltered workshops into the competitive work force successfully.

According to labor statistics, jobs should be available. Business is facing a labor shortage crisis resulting from the aging "baby boomers." The shortages for a variety of jobs, especially in the expanding service sector, will create a competitive market over the next 20 years for people with disabilities, who constitute a new, virtually untapped labor pool. Legislators can take advantage of this window of opportunity and offer leadership to expand supported employment programs for their citizens with disabilities.

Federal Activities

Federal programs that offer assistance in the areas of training and employment or provide civil rights protections for people with developmental disabilities include the following:

Americans with Disabilities Act of 1990 (P.L. 101-336). The ADA prohibits employers from discriminating against a qualified individual with a disability because of the disability. Beginning July 26, 1992, employers "engaged in an industry affecting commerce" who have 25 or more employees must make "reasonable accommodations" for persons with disabilities. Employers with

between 15 and 25 employees are required to comply beginning in July 1994. Some changes could include: making existing employee facilities accessible to and usable by individuals with disabilities, restructuring jobs, modifying work schedules, acquiring or modifying equipment or devices, and providing qualified readers or interpreters.

ADA Tax Credit. The Omnibus Budget Reconciliation Act of 1990 provides a tax credit for small businesses (those with gross receipts under $1 million or with 30 or fewer full-time employees during the preceding tax year) for expenses associated with providing "reasonable accommodation" in employment or in public accessibility under the Americans with Disabilities Act. Eligible businesses may receive a credit equal to 50 percent of the "eligible access expenditures" between $250 and $10,250 that are incurred for the purpose of complying with the ADA. Eligible expenditures include acquiring or modifying equipment or devices; providing interpreters or readers; and removing architectural, communication, physical, or transportation barriers.

Rehabilitation Act of 1973 (P.L. 93-112). This state-federal match program, known in most states as the vocational rehabilitation program, helps people with mental or physical disabilities find jobs. Amendments in 1986 (P.L. 99-506) created Title VI, which recognizes that people with severe disabilities can work competitively. Title VI establishes a new funding stream devoted solely to supported employment programs, although these funds represent only a small portion of the dollars states currently are spending on such programs. Title VI prohibits states from using their federal allocations to provide ongoing support services.

Job Training Partnership Act (JTPA) (P.L. 97-300). The JTPA provides monies for job training for people who are economically disadvantaged. Persons with disabilities are targeted under the JTPA, and funds may be used to educate private employers as well as to provide training and support services. In 1987-88, JTPA-sponsored services helped 46,350 adults and 47,740 youth with disabilities.[41]

Employment Opportunities for Disabled Americans Act (P.L. 99-643). This act includes work incentives that allow people with disabilities to work and not lose their benefits. One part of the law, Section 1619(a), allows people to earn money on the job and still keep all or part of their monthly Supplemental Security Income payments. The other part of the law, Section 1619(b), ensures that people can keep their Medicaid benefits as long as they need them to continue working, even if they are no longer getting a monthly SSI payment.

Targeted Jobs Tax Credit (TJTC). An important incentive to encourage employers to hire people with disabilities, the TJTC allows employers to claim a tax credit of 40 percent of the first $6,000 of qualified wages per eligible employee, with a maximum credit of $2,400 per employee during the first year of employment.

Technology-Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407). This act, which provides grants to states on a competitive basis, is intended to expand the availability of assistive technology services for persons with disabilities. Twenty-three states have been funded to develop consumer-responsive, statewide systems of assistive technology services for their citizens with disabilities. The Department of Education, National Institute on Disability and Rehabilitation Research, will be funding additional states each year, with the expectation that all 50 states, the District of Columbia, and the commonwealths and territories could receive assistance by 1995. The act also authorizes several federal studies and programs designed to improve the availability of assistive technology to individuals with disabilities, including the following: financing assistive technology devices and services; establishing a national information and program referral network; demonstrating innovative projects; providing technology training; and enhancing public awareness. More information may be obtained from the RESNA Technical Assistance Project, which is listed in Appendix C.

State Activities

Virginia, Washington, and Maryland, described here, have developed effective supported employment programs for people with disabilities. Similar programs are widespread and flourishing. Other states that have assumed leadership positions in supported employment programs include Colorado, Connecticut, Georgia, Minnesota, New Hampshire, and Oregon.

Virginia. Virginia assists over 2,000 people with developmental disabilities in supported employment. Start-up grants help programs convert from sheltered workshops to supported jobs. The state is working to have consumers pay for part of the costs of a job coach. This will be accomplished through federal work incentive initiatives such as Plan to Achieve Self Sufficiency (PASS) and Impairment-Related Work Expense (IRWE). These federal programs allow the consumer to write off the costs of transportation, assistive technology, and a job coach against earnings when calibrating income for SSI eligibility.[42]

(Contact: Mark Peterson, program supervisor for supported employment, Department of Rehabilitative Services, 4901 Fitzhugh Ave., Richmond, Virginia 23230; (804) 367-0279.)

Washington. The Washington Division of Developmental Disabilities has taken a leadership role in encouraging counties to develop job programs in integrated community settings. Of the 3,440 people in all vocational programs in Washington, 1,400 are in supported employment. The Washington Supported Employment Initiative, created with a grant from the federal Office of Special Education and Rehabilitative Services (OSERS), has a long-range goal to change the way union and business officials think about people with disabilities. The initiative aims to look beyond entry-level and high-turnover jobs to better-paying jobs for people with disabilities.[43]

(Contact: Lee Valenta, director, Washington Initiative for Supported Employment, 83 South King, Suite 410, Seattle, Washington 98104; (206) 343-0881.)

Maryland. In Maryland, the state Developmental Disabilities Administration publicly endorsed the principle that people with disabilities have the right to lead a normal life, including holding a job. The administration announced that 85 percent of all expansion money would go to supported employment. Working with day program operators, the administration determined that 65 percent of the consumers could be served in supported employment and established that figure as a goal. The program began in 1985 with a five-year federal OSERS grant administered by The Kennedy Institute.

When the grant expired in September 1990, the state had converted approximately 50 percent of its day program positions to supported employment, one of the best records in the country. The rates of conversion differ widely among regions, with more conversions completed in the southern part of the state around Washington, D.C., and fewer in the western rural mountain region. By 1989, approximately 1,100 people with disabilities had supported jobs with 268 employers, including Marriott Hotels, Pizza Hut, Radio Shack, J.C. Penney, Red Lobster, and Ramada Inns. Consumers earn an average hourly wage of $3.68 and work an average of 29.7 hours per month. A 1988 evaluation found that more than one-half of the employees stayed at the job and earned increasingly higher wages. The state is applying for an extension to the OSERS grant to be able to continue converting day program positions to supported employment.[44]

(Contact: Cynthia Kauffman, director of the Department for Family Support Services, The Kennedy Institute, 2911 East Biddle Street, Baltimore, Maryland 21213; (301) 550-9700.)

Pub. 910 3002

Recommendations for State Action

The NCSL Task Force on Developmental Disabilities recommends that state legislatures do the following in the area of supported employment:

a) Encourage the formation of strong public-private partnerships to promote the value of employing people with developmental disabilities. Enact legislative incentives, such as tax credits, so that businesses can incorporate people with developmental disabilities into the work force.

b) Form a public-private task force to assist with implementation of the employment discrimination provisions contained within the federal Americans with Disabilities Act.

c) Encourage state-supported programs to empower persons with disabilities to make choices for themselves about their job interests and capabilities.

d) Encourage service providers to help people in day programs or sheltered workshops move into supported employment through the use of flexible state agency guidelines, start-up grants, redirection of existing financial resources, and new funds targeted toward supported employment.

e) Encourage state and local governments to hire people with disabilities for public sector jobs.

f) Take maximum advantage of existing federal programs such as the Job Training Partnership Act and the Rehabilitation Act.

g) Provide funding for long-term vocational support, since most people with disabilities need periodic or continual assistance for the duration of their employment.

h) Encourage both public and private employers to develop stable jobs that provide fringe benefits for people with disabilities, aiming beyond low-level, high-turnover jobs.

i) Ensure access to supported employment for all individuals with developmental disabilities, including people with physical disabilities and traumatic brain injury.

j) Monitor the quality and effectiveness of supported employment programs and obtain input from consumers of services.

k) Provide incentives for community employers to hire job coaches, and require state agencies to hire job coaches.

l) Support programs that encourage co-worker support and interaction in the work place.

Pub. 910 3002

FUNDING

Aaron was born prematurely with cerebral palsy and sensory impairments. He needs a tracheostomy tube to help him breathe; a gastrointestinal tube to help him eat; and other extensive medical, health, and social supports. Aaron's mother, father, and brother want him to live with them at home. Because no single funding source is flexible enough to meet all of the youngster's and his family's unique needs, the family uses a combination of private, local, state, and federal resources.

Private health insurance covers medical and dental care, hospitalization, some medicines, Aaron's special food formula, his wheelchair, and some other equipment. Aaron is eligible for some Medicaid waiver program home-based services and equipment that the family's private insurance does not cover, such as a home health aide to be with him at home after school. The state's Family Support Program allowance of $250 per month covers physical therapy at home, with his parents assisting, and other special needs, such as the lift on the family van. Aaron and his family also receive supportive home care under their state's Community Options Program and respite care through a county developmental disabilities agency, which is partially state-funded. Aaron now attends a typical class in a regular neighborhood school, with supports for both himself and his teacher. Even though it's complicated, the funding puzzle helps ensure that Aaron lives at home and not in an institution, which could cost more than $50,000 annually, and that he gets the quality services he and his family need.

Introduction

Each year, federal, state, and local governments spend over $11.7 billion to care for people with developmental disabilities. State and local government revenues account for $7.4 billion of that amount. The development of community services for persons with developmental disabilities has been fueled largely by state initiatives. States provide 74.6 percent of the funding for community services for people with developmental disabilities, amounting to $4.2 billion in 1988. In addition, state and local governments spend over $3.1 billion annually on institutions and large private facilities.[45]

Medicaid provides the bulk of federal funds used by states to finance services for persons with developmental disabilities. Unfortunately, Medicaid regulations severely restrict reimbursements for community-based services, unless exceptions are made through a waiver. Requirements of Medicaid's Intermediate Care Facilities for the Mentally Retarded program prevent facilities that serve fewer than four people from qualifying for ICF/MR certification and reimbursement. These federal policies are out of step with important values and contemporary directions in state service delivery. As a result, many states have viewed placing people in state institutions or larger group home settings as the only way to secure federal support for people with more intensive service needs. This eligibility criterion clearly frustrates the objectives that promote self-sufficiency and integration into the community.

In FY 1988, the federal government reimbursed states $2.39 billion for institutional care through the ICFs/MR program, while spending only $252 million of Medicaid funds for home- and community-based waiver services for people with developmental disabilities.[46] States are caught in a bind: parents, consumers, and advocates are demanding flexible, tailored services for people in

their own homes, or their families' homes. Yet Medicaid reimbursement policies will pay only for services in institutions, or, under a waiver, for people who would otherwise require institutional care.

States can be more proactive in establishing policy for effective programs for persons with developmental disabilities. States can establish their own goals distinct from federal policy, and fund programs to ensure that the goals are achieved. Increasingly, states are turning to creative funding mechanisms or creative uses of existing federal programs to reach their service goals for citizens with developmental disabilities. These include the following:

- *Expanded use of the Home- and Community-Based Services waiver and the Model Waiver Option.* Despite the so-called "cold bed" policy, which requires states to prove that people served under an HCBS waiver would otherwise be moved into an ICF/MR bed, many states have made wide use of this waiver authority. North Dakota serves 1,300 people through its waiver program and Colorado serves 2,200 people, despite relatively small populations in these states.[47] Many states have used Medicaid HCBS waivers as a way to test and implement service approaches that are not based on group homes. Supported living is being financed with home- and community-based waiver dollars in Arkansas, Colorado, Minnesota, Missouri, North Dakota, Washington, and Wisconsin. Other states, including Connecticut, Illinois, Ohio, Oklahoma, and Virginia, are planning to use waiver dollars to cover the cost of such services.[48] In addition, states are serving targeted groups of people with particular kinds of needs through the Model Waiver Option, though participation is limited to 200 participants per waiver program.

- *Selected use of Medicaid state plan options.* In addition to the services states must provide under Medicaid, states also may choose to cover up to 34 optional services at their discretion. Examples of service options that may be used by states for people with developmental disabilities are personal care services, clinic services, rehabilitative services, and "targeted case management." Federal Medicaid restrictions require covered services to be available statewide and to be of equal scope across all groups of Medicaid-eligible persons. To meet those requirements and still keep their costs down, some states have defined a particular service in the state plan in such a manner that only people with developmental disabilities could use it. Unlike other state plan options, targeted case management can be applied to a specific subpopulation of potentially eligible recipients, such as people with developmental disabilities, and does not have to be offered statewide. The targeted case management option has been used in states such as Massachusetts, Michigan, Texas, and Wisconsin to serve people with developmental disabilities.[49]

- *Targeted assistance to providers.* Providers need help to make the transition from old models of facility-based services to newer, person-centered services. For example, some states are offering financial incentives to providers who place a person in supported employment rather than in a sheltered workshop.

- *Flexible payment mechanisms.* Public dollars are best employed when services and supports can be tailored to individual needs. Some states are instituting individualized payment mechanisms where the individual determines what services and supports he or she needs and selects a provider. The provider then bills the state developmental disability agency. Other states are using a voucher system, where individuals can select the services they need from a provider of their choice. In both these approaches, the power resides with the consumer, and the provider must adjust to meet consumer needs.

States will continue to develop creative ways of financing those services that emphasize individual choice. In this effort, consumers and families should be full participants in developing various financing and payment strategies to ensure that the results are consistent with essential principles of consumer empowerment.

Why Legislators Should Be Concerned

States cannot expect significant increases in federal assistance for services to people with developmental disabilities. The federal deficit is too large and too structural, and the so-called "peace dividend" is being consumed by the military activities in the Persian Gulf region and by the "savings & loan" crisis. Strained state budgets also are unlikely to yield significant funding increases. Nevertheless, states face rapidly escalating service demands.

Given this fiscal reality, states must develop funding mechanisms to support programs that yield the most cost-effective results. In general, it is not cost-effective to maintain someone in an institution for $56,042 a year (the average annual per capita cost of care in a state mental retardation institution during 1988). Community services and home supports can meet the needs of consumers and parents and can help develop independent, participating citizens.

After studying the fiscal consequences of continued use of existing service models, the Ohio Department of Mental Retardation and Developmental Disabilities concluded that its budget would have to increase by 174 percent over the next 10 years in order to meet the needs of the 70,000 people estimated to require services by FY 2000-2001. However, if the department begins to give increased emphasis to service interventions that are aimed at decreasing the dependency of people with disabilities on formal, structured, service programs, the same full-service goal could be achieved with an estimated 59 percent increase in the department's budget over the same 10-year period.[50]

States around the nation will have to examine both service goals and approaches before synchronizing funding policies with consumers' needs, reallocation of resources, and affordability.

Federal Activities

Significant federal money is available to support people with developmental disabilities. With careful planning, states can take maximum advantage of federal support and stretch state dollars. Available funding comes from the following programs:

Medicaid. As described throughout this publication, Medicaid is the largest source of federal funding for programs that serve persons with developmental disabilities. The ICFs/MR program option is discussed on pages 23 and 32, and the Medicaid Home- and Community-Based Services waiver program and the Model Waiver Option are discussed on page 10. Frequent changes in coverage and complicated application procedures often prevent states from taking full advantage of available Medicaid funds. Some recent changes in Medicaid coverage that affect people with disabilities include the following:

- *COBRA-85.* The Consolidated Omnibus Budget Reconciliation Act of 1985 allows states to offer case management as an optional Medicaid-funded service.

- *OBRA-86.* The Omnibus Budget Reconciliation Act of 1986 authorizes state Medicaid coverage of at-home respiratory care service for individuals who need a ventilator.

- *OBRA-87.* The Omnibus Budget Reconciliation Act of 1987 requires nursing homes that receive federal funds to place residents with disabilities who do not require 24-hour nursing in less restrictive settings.

- *OBRA-89.* The Omnibus Budget Reconciliation Act of 1989 requires states to provide treatment to correct physical or mental problems identified in Medicaid-eligible children and youth during the Early and Periodic Screening, Diagnosis and Treatment health testing, as described on page 3.

- *OBRA-90.* As described on page 23, the Omnibus Budget Reconciliation Act of 1990 establishes a Community Supported Living Arrangements Medicaid option for up to eight states.

Other. More information about federal funding for early intervention, family support, transition services, community living, and supported employment are covered under those topics in this publication.

State Activities

North Dakota. This state uses an innovative individualized payment method to pay for its Independent Supported Living Arrangements (ISLA) program, which was implemented in April 1987 and now serves over 500 people. A contract is written for each individual, establishing a flat payment rate per person based on the necessary level of support needed to maintain him or her in an apartment or family home setting. Because the program is financed through a Medicaid Home- and Community-Based Services waiver, two basic rates are used: one for services costs, which are reimbursable under the HCBS waiver; and the other for room and board costs, which are not.

Service costs are determined by the number of staff hours needed to enable a person with a disability to live independently. For example, if the provider agency's staff is expected to be on the premises four hours per day, then the payment rate for the individual will reflect the salaries and fringe benefits of that level of staff intensity. Providers also are reimbursed for other service expenses, administrative costs, and overall program management.

Room and board costs are determined based on the costs of rent, utilities, food, and related items subtracted from the recipient's income, including Supplemental Security Income, food stamps, and job salary. If room and board costs exceed the individual's expected income, the state makes a supplementary payment to the provider. The provider is paid the flat rate outlined in each individual contract. If services can be provided more economically, the provider benefits. The rate, however, is revised after actual provider costs are reviewed.

The program has established a strong track record of using state and federal dollars effectively. Daily program costs (excluding a recipient's room and board payment) are $39.54 per day. The average daily costs of the prior placements of program participants was $51.19 per day. On an annualized basis, program cost savings are estimated to be more than $1.9 million.[51]

(Contact: Russ Pittsley, administrator, Program Operations and Services Unit, Developmental Disabilities Division, Bismarck, North Dakota 58505; (701) 224-2768; statutory citation: N.D. Cent. Code sec. 25-01.2.)

Illinois. Illinois was a pioneer in establishing a Self-Sufficiency Trust, which allows parents of a family member with a disability to contribute money to a Private Trust Fund, where the money is pooled with that of other participating families. Returns on investments are credited proportionately to each family. Interest earned from this pooled trust, is transferred to the counterpart State Trust Fund, which pays for supplemental goods or services via the existing service network. A life-care plan, developed for each participant, embodies the wishes of the parents and defines the intent and nature of supplemental services that will be provided to the beneficiary with disabilities. Because contributions technically become State Trust Fund monies, they are not viewed as earned or unearned income to the beneficiary with disabilities. Eligibility for government programs, such as Supplemental Security Income and Medicaid, is not affected. Upon the death of a beneficiary, 50 percent of the residual principal is donated to a second fund, the Charitable Fund, which is used for low-income and indigent persons with disabilities who are unable to participate in the Private Trust Fund. In addition to Illinois, Alaska, Kansas, Maine, Montana, Oregon, and Rhode Island have passed legislation allowing establishment of Self-Sufficiency Trusts.[52]

(Contact: Paul Medlin, senior vice president, National Foundation for People with Disabilities, 340 W. Butterfield Road, Suite 3C, Elmhurst, Illinois 60126; (708) 832-9700; statutory citation: Ill. Rev. Stat. ch. 91 1/2, sec. 5-118; note: the foundation has copyrighted the Self-Sufficiency Trust.)

Montana. Provider organizations serving people with developmental disabilities and mental illness may obtain low-interest loans through the Community Provider Pooled Loan Program. By pooling the risk, the program is able to offer loans to providers who would have difficulty obtaining credit in the open market. Loans are used to buy vehicles, computers, and other equipment; construct or renovate facilities; or refinance existing loans at a lower rate. The program was started in 1988 with an initial bond issue of $1.5 million. In 1990, $6.9 million in tax-free bonds were sold to fund the program, which will offer providers interest rates of around 7 3/4 percent. Of this amount, $4.6 million will be used for providers of services to persons with developmental disabilities. By reducing existing debt service costs, Montana has been able to free up resources to expand services.[53]

(Contact: Dennis M. Taylor, division administrator, Montana Department of Social and Rehabilitation Services, Developmental Disabilities Division, P.O. Box 4210, Helena, Montana 59604; (406) 444-2995; statutory citation: Mont. Code Ann. sec. 90-7-1.)

Nevada. This state uses an incentive system to finance individuals in supported employment. Providers who place an individual into community work outside of sheltered workshops during the first 90-day period receive reimbursement up to three times the usual workshop rate per capita. During the second 90 days of supported employment, the payment decreases to twice the workshop rate per capita. After the initial six months, as the individual becomes assimilated into the employment, the reimbursement tapers off to a level at which the provider can purchase periodic case management follow-up services.[54]

(Contact: Donny Loux, chief of community programs and development, Department of Rehabilitation, 505 East King Street, Room 502, Carson City, Nevada 98710; (702) 687-4452.)

Massachusetts. Early intervention services in Massachusetts are now funded through a unit billing system, which pays providers a set fee for a particular service. Under the previous system, the state would pay a center to have a social worker on staff, regardless of the number of consumers served by the social worker. Under the new system, the state pays the center for each unit of service delivered. This system requires more efficiency from both the provider and the purchaser, which is the Massachusetts Division of Early Childhood in the Department of Public Health, the lead agency for early intervention services.

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To implement this system, the division performed extensive analysis on typical services and all costs related to those services. The division conducted a time-motion study of early intervention in which 800 service personnel were asked to keep time sheets on what they did in 15-minute increments. Working closely with the Massachusetts Rate Setting Commission, the division was able to use data from this survey to classify all early intervention services into six one-hour units of service: home visit, assessment, screening, center-based individual service, center-based child-focused group, and center-based parent-focused group. The consumer is not aware of the billing system. Services are based on individual needs, as determined by the Individualized Family Service Plan.

The unit billing system facilitates payment from third-party payers, such as Medicaid and insurance companies. In January 1990, the Massachusetts General Court (the legislature) required all private, third-party insurance companies doing business in the state to cover early intervention services. Since 55 percent of the early intervention consumers in the state have third-party insurance coverage, the early intervention program will be able to bill approximately one-half of the health-related costs of services to private insurance companies by the end of the year. The education-related costs will be picked up by the state public health agency.

The unit billing plan has increased the efficiency of the early intervention system, allowing Massachusetts to increase the number of consumers served by 600 per year, while state funding remained stable. In FY 1989-90, Massachusetts served 7,110 children between birth and age three.[55]

(Contact: Karl Kastorf, director of the Division of Early Childhood, Department of Public Health, 150 Tremont, 2nd Floor, Boston, Massachusetts 02111; (617) 727-5090.)

Recommendations for State Action

The NCSL Task Force on Developmental Disabilities recommends that state legislatures do the following in the area of funding:

a) Develop financial goals, based on values that empower individuals, for community services and support systems for persons with developmental disabilities.

b) Provide fiscal incentives and technical assistance to help service providers move from center-based early intervention, employment, or residential care to community-integrated and individualized approaches to early intervention, supported employment, and housing.

c) Take advantage of the full range of federal funds and options under current law.

d) Work with business and industry to develop creative public/private financing mechanisms, such as state high-risk pools, state subsidies for private health insurance, state-financed catastrophic health insurance, or a Self-Sufficiency Trust.

e) Examine pay levels of community-based personnel, as compared with institutionally based personnel, to try to reduce turnover and increase quality.

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APPENDIX A

NCSL Memorial on Persons With Developmental Disabilities and Their Families

(Adopted at the NCSL Annual Business Meeting, August 9, 1990)

The Task Force on Developmental Disabilities of the National Conference of State Legislatures believes that individuals with developmental disabilities, including mental retardation, autism, cerebral palsy, epilepsy, and related conditions, are first and foremost unique individuals with basic human needs, aspirations, desires, and feelings and are citizens with the same rights, privileges, opportunities, and responsibilities afforded other citizens of the United States.

Persons with developmental disabilities and their families should have the right to make decisions for themselves, to live in homes of their choice and with whom they choose, and to exercise their full rights and responsibilities as citizens.

The Task Force on Developmental Disabilities believes that all persons with developmental disabilities and their families should be protected from discrimination, should be encouraged and allowed to achieve their full potentials, and should be treated with dignity and respect.

The Task Force on Developmental Disabilities further believes that persons with developmental disabilities should have the opportunity to live, learn, work, and play in environments that enhance their functional skills, productivity, independence, social support networks, and integration into general community life, with access to the full range of assistive technology.

The Task Force on Developmental Disabilities recognizes that families are the primary source of care, nurture, and support for children and adults with developmental disabilities. When children with developmental disabilities cannot live with their biological family, they should be able to receive care, nurture, and support in a family setting.

To promote their development to the fullest extent possible, children with developmental disabilities need early intervention to identify potential disabilities and to ensure appropriate services or education provided in appropriate environments.

Support services for persons with developmental disabilities should be individualized, flexible over time, and built on strengths and needs. The services should be designed to assure physical health and safety, development of skills for independent living and productivity, relationships with families and friends, and a high quality of life for individuals, regardless of where they live.

The Task Force on Developmental Disabilities supports service systems for persons with developmental disabilities that are affordable, accountable, accessible, and culturally appropriate; that identify each individual's strengths and needs; that provide needed supports and services within available resources; that respect the choices and rights of participants; and that involve individuals with developmental disabilities and their families in all aspects of development, implementation, monitoring, and evaluation of these supports and services.

APPENDIX B

Fiscal Effort for MR/DD Services in Fiscal Years 1988 and 1977, by State

State	COMMUNITY 1988	COMMUNITY 1977	CONGREGATE 1988	CONGREGATE 1977	TOTAL MR/DD 1988	TOTAL MR/DD 1977
North Dakota	1	51	1	3	1	14
Rhode Island	2	15	27	5	5	8
District of Columbia	3	50	23	9	6	21
Connecticut	4	30	9	14	3	19
New York	5	17	3	1	2	1
Minnesota	6	2	10	7	7	2
Michigan	7	35	47	20	21	28
New Hampshire	8	25	44	44	18	41
Massachusetts	9	11	2	17	4	13
South Dakota	10	27	14	6	9	10
Vermont	11	32	24	8	13	11
Ohio	12	10	16	41	10	25
Pennsylvania	13	12	18	2	11	4
Montana	14	4	33	15	16	6
Iowa	15	1	5	28	8	3
Maine	16	20	30	36	19	31
Nebraska	17	3	37	34	24	9
Colorado	18	8	50	37	40	23
Utah	19	45	19	29	17	42
Wisconsin	20	6	21	4	20	5
Idaho	21	13	32	23	25	37
Maryland	22	33	40	39	32	37
Alaska	23	14	48	49	41	44
Wyoming	24	18	4	19	12	18
California	25	9	42	48	39	34
New Jersey	26	39	20	30	22	40
South Carolina	27	26	6	10	14	12
Oregon	28	44	17	16	23	27
Louisiana	29	43	7	18	15	29
Indiana	30	22	38	47	38	43
Missouri	31	21	25	32	29	30
Georgia	32	7	31	25	36	16
Illinois	33	24	29	21	33	24
Arizona	34	49	49	46	48	49
Delaware	35	48	22	42	30	47
New Mexico	36	36	39	35	42	39
Washington	37	31	28	31	35	35
Kansas	38	5	15	12	27	7
North Carolina	39	23	12	11	26	15
Arkansas	40	16	13	24	28	22
Florida	41	38	45	43	49	45
West Virginia	42	47	41	45	46	48
Kentucky	43	41	43	50	47	50
Texas	44	34	26	13	37	20
Virginia	45	29	34	22	43	26
Hawaii	46	19	46	38	50	32
Alabama	47	28	36	26	44	33
Tennessee	48	37	35	33	45	38
Nevada	49	40	51	51	51	51
Oklahoma	50	46	11	40	34	46
Mississippi	51	42	8	27	31	36

Note: States are ranked and listed by 1988 Community MR/DD spending as a percentage of personal income. Ranks for community, congregate, and total MR/DD spending as a percentage of personal income also are indicated for 1988 and 1977. The source also reports for each state a cumulative ranking for 1977 through 1988, which consists of adjusted annual spending accumulated divided by adjusted personal income accumulated.

Source: Braddock et al., *The State of the States in Developmental Disabilities* (Baltimore: Brookes Publishing Company, 1989), p. 27.

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APPENDIX C

Resources

State Resources

Each state has a number of resources that can provide legislators and other interested people with information about their own state's programs and services for persons with developmental disabilities, which may include the following: the state agency that administers services for persons with developmental disabilities; a developmental disabilities planning council; a protection and advocacy system; a university-affiliated program in developmental disabilities; an association for retarded citizens; and a united cerebral palsy association. A national counterpart for each of these resources is listed in this Appendix, which may be able to refer interested persons to state-based resources.

National Resources[56]

Administration on Developmental Disabilities
Department of Health and Human Services
200 Independence Avenue, S.W., Room 336-D
Washington, D.C. 20201
(202) 245-2890

Acts as the lead agency within the federal Department of Health and Human Services to plan and carry out programs that promote the self-sufficiency and protect the rights of Americans with developmental disabilities. Works in partnership with state governments, local communities, and the private sector to increase the social and economic integration of individuals with developmental disabilities into the fabric of society. Programs address all elements of the life cycle, including prevention, diagnosis, early intervention, therapy, education, training, employment, community living, and leisure opportunities. Administers four grant programs: Basic State Grant Program; Protection and Advocacy Program, University Affiliated Programs (UAP); and Projects of National Significance.

American Association of University Affiliated Programs for Persons with Developmental Disabilities
8630 Fenton Street, Suite 410
Silver Spring, Maryland 20910-3803
(301) 588-8252

Acts as the national organization for university-based or affiliated clinical service and interdisciplinary training centers for graduate students and others interested in the fields of mental retardation and other developmental disabilities. Provides coordination of federal funding for programs, technical assistance to Congress, information exchange among members, and educational activities about programs. Publications: *AAUAP Network News*, quarterly; *Resource Directory*, annual; *Developmental Handicaps: Prevention and Treatment*; and *Prevention Update*.

American Association on Mental Retardation
1719 Kalorama Road, N.W.
Washington, D.C. 20009
(202) 387-1968 1 (800) 424-3688

Promotes the well-being of individuals with mental retardation and supports those who work in the field. Helps review and shape public policy and encourages research and education. Promotes quality services for people with mental retardation

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and their families. Publications: *Mental Retardation*, bimonthly; and *The American Journal on Mental Retardation*, bimonthly.

The Association for Persons with Severe Handicaps
7010 Roosevelt Way, N.E.
Seattle, Washington 98115
(206) 523-8446

Seeks to ensure an autonomous, dignified lifestyle for all people with severe disabilities. Advocates quality education from birth through adulthood for individuals with disabilities. Disseminates updated information on solutions to problems, research findings, trends, and practices relevant to people with severe disabilities. Publications: *DC Update*, bimonthly; *Journal of the Association for Persons with Severe Handicaps*, quarterly; and *TASH Newsletter*, monthly.

Association for Retarded Citizens
2501 Avenue J
P.O. Box 6109
Arlington, Texas 76005
(817) 640-0204

Works on local, state, and national levels to promote services, research, public understanding, and legislation for people with mental retardation and their families. Publications: *the arc*, six times a year; and *ARC Government Report*, biweekly.

Center on Human Policy
200 Huntington Hall
Syracuse University
Syracuse, New York 13244
(315) 443-3851

Promotes the integration of persons with severe disabilities into the mainstream of society. Disseminates information to families, human services professionals, policymakers, and others on laws, regulations, and programs affecting people with disabilities. Documents outstanding community living and educational programs and assists in creating exemplary services. Evaluates public policies to determine their impact on people with disabilities. Publishes research reports, analyses, and information bulletins.

The Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091
(703) 620-3660

Provides information to teachers, parents, and others concerning the education of exceptional children. Provides technical assistance to legislators, state departments of education, and other agencies. Coordinates political action networks to support the rights of exceptional people. Publications: *Exceptional Children*, quarterly; and *Teaching Exceptional Children*, six times a year.

Division of Services for Children with Special Health Needs
Department of Health and Human Services
Parklawn Building, 5600 Fishers Lane
Rockville, Maryland 20857
(301) 443-2350

Administers the part of the Maternal and Child Health block grant relating to children with special needs. Funds discretionary grants to provide services for children with special health needs and their families. Provides material on all aspects of children with special health needs through the Maternal and Child Health Clearinghouse.

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, Massachusetts 02140
(617) 876-0426

Helps elected officials and public administrators manage and improve programs for people with developmental disabilities or mental illness. Participates in the formulation of federal program legislation, regulations, and guidelines, and in the development of state and local area developmental disabilities and mental health program plans. Conducts evaluations at the federal, state, and local program levels. Conducts studies of the magnitude of mental and physical disabilities in order to assess service needs. Publications: *Family Support Services in the United States: An End of Decade Status Report*; and *Financing Options for Home Care for Children With Chronic Illness and Severe Disability: Technical Assistance Manual.*

Institute on Community Integration (UAP)
University of Minnesota, 101 Pattee Hall
150 Pillsbury Drive, S.E.
Minneapolis, Minnesota 55455
(612) 624-4848

Brings together the research, training, and community service programs of the Minnesota University Affiliated Program on Developmental Disabilities, the Research and Training Center on Community Living, and the Center for Residential and Community Services. Research includes a national data base on residential and related services; a longitudinal study of persons moving from institutional to community living arrangements; and numerous national, state, and local policy and program evaluation studies. Training and community service projects cover infants to elderly persons with disabilities. Publications: *IMPACT*, quarterly; *Policy Research Brief*, three times a year; and numerous reports, including the *1990 Chartbook on Services for Persons with Developmental Disabilities*.

The National Association of Developmental Disabilities Councils
1234 Massachusetts Avenue, N.W., Suite 103
Washington, D.C. 20005
(202) 347-1234

Promotes cooperation and communication among federal agencies, state governments, volunteer groups, individual state and territorial councils, and other organizations. Represents the views of state developmental disabilities councils in Washington, D.C. Publications: *Forum*, bimonthly; and *Forging a New Era: The 1990 Reports on People with Developmental Disabilities*.

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National Association of Protection & Advocacy Systems
900 Second Street, N.E., Suite 211
Washington, D.C. 20002
(202) 408-9514

Serves the executive directors and designees of state and territorial protection and advocacy systems and client assistance programs for persons with developmental disabilities and mental illness. Furthers the human, civil, and legal rights of persons with disabilities. Advances the interests of protection and advocacy systems. Facilitates coordination and support among such systems to enhance their capacity to provide optimal services. Publication: *State Protection and Advocacy Agencies*, annual directory.

National Association of State Mental Retardation Program Directors, Inc.
113 Oronoco Street
Alexandria, Virginia 22314
(703) 683-4202

Monitors and reports on administrative, legislative, and judicial activities that affect programs concerning mental retardation. Provides technical assistance services. Publications: *Capitol Capsule*, monthly; *Federal Funding Inquiry*, periodic; *New Directions*, monthly; and *The Community Services Reporter*, bimonthly.

National Early Childhood Technical Assistance System (NEC*TAS)
Carolina Policy Studies Program
Frank Porter Graham Child Development Center
University of North Carolina at Chapel Hill
137 East Franklin Street, 500 NCNB Plaza
Chapel Hill, North Carolina 27514
(919) 962-7374

Designs and provides technical assistance to state agencies designated to implement P.L. 99-457, the Program for Infants, Toddlers, and Families (also referred to as "Part H") and the preschool program. Provides selected publications and resource referral to other organizations on request. Consists of six organizations funded by the Office of Special Education Programs in the U.S. Department of Education: Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill; Child Development Center, Georgetown University; Department of Special Education, University of Hawaii at Manoa; National Association of State Directors of Special Education, Washington, D.C.; National Center for Clinical Infant Programs, Arlington, Virginia; and National Parent Network on Disabilities, Boston, Massachusetts. Publications: *Directory of Selected Early Childhood Programs*, annual.

National Foundation for People with Disabilities
340 W. Butterfield Road, Suite 3-C
Elmhurst, Illinois 60126
(708) 832-9700

Seeks to facilitate life enrichment opportunities for people with mental and/or physical disabilities and to educate the general population about the contributions people with disabilities can make, given the opportunity. Operates the Anna Emery Hanson Center for the Arts and the Disabled; and the Self-Sufficiency Trust, a private sector, life care, estate planning mechanism designed to allow families with dependents who are disabled a barrier-free means of providing supplemental services using private dollars. Currently is sponsoring the development of a six-part public television series about people with disabilities and their contribution to society, entitled "Imagine This World." Publications: *Response*, quarterly; *Self-Sufficiency Trust Pre-Legislative Orientation Handbook*; and *Self-Sufficiency Trust-Illinois Attorney Handbook*.

Office of Special Education and Rehabilitative Services
Department of Education, Switzer Building
330 C Street, S.W.
Washington, D.C. 20202
(202) 732-1427

Provides formula grant money to states to administer special education and rehabilitative services to children, youth, and adults with disabilities. Conducts research through discretionary grant programs to improve the quality of life for people with disabilities. Publications: *OSERS News in Print*, quarterly.

RESNA Technical Assistance Project
1101 Connecticut Avenue, N.W., Suite 700
Washington, D.C. 20036
(202) 857-1140 Voice/TDD

Provides technical assistance and information to states on the development and implementation of a consumer-responsive statewide program of technology-related assistance under the federal Technology-Related Assistance for Individuals with Disabilities Act of 1988. Publications: *A.T. Quarterly*, newsletter; directory of consultants in assistive technology services; and other written materials.

United Cerebral Palsy Associations, Inc.
1522 K Street, N.W., Suite 1112
Washington, D.C. 20005
(202) 842-1266/1 (800) 872-5827

Seeks to ensure the rights and entitlements of people with disabilities. Helps equip and enable individuals with cerebral palsy and other severe disabilities to attain the fullest possible employment, productivity, and participation in an integrated community. Provides factual material for awareness and understanding on the part of all segments of the public. Mobilizes human and financial resources to accomplish these goals. Publications: *Word From Washington*, bimonthly; *The Networker*, quarterly; *Family Support Bulletin*, quarterly; *The UCPA Employment Manual*; *The UCPA Technology Manual*; and *The UCPA Manual: Community Residential Support Services for Persons With Head Injury*.

University Affiliated Program in Developmental Disabilities
The University of Illinois at Chicago
1640 West Roosevelt Road (M/C 627)
Chicago, Illinois 60608
(312) 413-1647

Educates government policymakers through applied research, information dissemination, and technical assistance. Has developed model programs and community training and has major UAP initiatives in: family studies and services, pre-service and outreach training for graduate students and community service organizations, model assistive technology services, and public policy analysis. Publications: *Public Policy Monograph Series*, with more than 50 documents; and a quarterly newsletter. Also supports extensive publication in journal articles, books, book chapters and special reports. Related publications: *The State of the States in Developmental Disabilities*, by David Braddock et al. (refer to item 3 in the Notes); and *Federal Policy toward Mental Retardation and Developmental Disabilities*, also by David Braddock, 1987.

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NOTES

1. U.S. Department of Health and Human Services, Office of Human Development Services, August, 1989: press release.

2. Robert M. Gettings, Executive Director, National Association of State Mental Retardation Program Directors, October 9, 1990: personal communication.

3. David Braddock et al., *The State of the States in Developmental Disabilities* (Baltimore, Md.: Paul H. Brookes Publishing Co., 1990), p. 21.

4. *The 11th Annual Report to Congress on the Implementation of the Education for All Handicapped Children Act* (Washington, D.C.: U.S. Department of Education, 1989).

5. Gloria Harbin, associate director, Carolina Policy Studies Program, University of North Carolina at Chapel Hill, October 9, 1990: telephone conversation (919) 962-7371.

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ACRONYMS

ADA -- The federal Americans with Disabilities Act of 1990.

CSLA -- The federal Community Supported Living Arrangements option under Medicaid.

EHA -- The federal Education of the Handicapped Act (now called IDEA).

EPSDT -- Early and Periodic Screening, Diagnosis and Treatment (a Medicaid service).

FHAA -- The federal Fair Housing Amendments Act.

FPL -- Federal Poverty Level ($10,560 for a family of three in 1990).

HCBS -- Home- and Community-Based Services, a waiver program under Medicaid.

ICF/MR -- Intermediate Care Facility for the Mentally Retarded.

ICFs/MR -- Intermediate Care Facilities for the Mentally Retarded.

IDEA -- The federal Individuals with Disabilities Education Act (formerly called the Education of the Handicapped Act).

IEP -- Individualized Education Program.

IFSP -- Individualized Family Service Plan.

IRWE -- The federal Impairment-Related Work Expense.

JTPA -- The federal Job Training Partnership Act.

MR/DD -- Mental retardation/developmental disabilities.

OSERS -- The federal Office of Special Education and Rehabilitative Services.

PASS -- The federal Plan to Achieve Self Sufficiency.

SSI -- Supplemental Security Income.

TEFRA -- The federal Tax Equity and Fiscal Responsibility Act of 1982.

TJTC -- The federal Targeted Jobs Tax Credit.

Pub. 910 3002

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